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## PUBLICATIONS 2014
This document describes the most significant results achieved through the healthcare and research activities undertaken by Bambino Gesù Paediatric Hospital (OPBG) in 2014. The information set out in this publication shows the constant growth achieved by OPBG under the modernisation and international development programme it has undertaken in recent years.

Our hospital's history, developed over a period of 145 years, is marked by a number of significant achievements resulting in its recognition as the most important paediatric institution in Italy and among the leading paediatric hospitals throughout the world. Among the many objectives achieved in 2014, we believe it important to highlight the opening of the new San Paolo Fuori le Mura research laboratories. These host the hospital’s main research activities, and in particular those relating to biomolecular and metabolic research, as well as the hospital’s genetic diagnostic services and a cell factory for the development and production of medicinal products for gene, cellular and tissue engineering therapy, and of vectors, antibodies and medicinal products for clinical trials.

Scientific activity saw in 2014 a further substantial increase in the number of peer reviewed publications, which have been over 550, achieving an overall Impact Factor of 2,119 points. These results represent an increase by over 25% of the already outstanding results achieved in the previous year, and place our institution among the five leading Italian institutions and at the top of the paediatric ones.

Health care activity, as part of an approach driven by clinical appropriateness, has further increased outpatient paediatric surgery. The hospital as thus taken a prominent role nationally, in terms of operations, in this particular sector. We have also consolidated the already considerable volumes of solid organ and bone marrow transplantations, confirming the Hospital's position as a national benchmark in paediatric transplant activities. We should note, lastly, the innovative nursing project involving assessment and management of pain for all patients within the Hospital, which demonstrates our unstinting commitment to the creation of a 'Pain-Free-Hospital'.

This report essentially illustrates the commitment of all personnel working at OPBG to the ongoing improvement in the quality of their work. The results achieved are the fruits of the collective effort of a cohesive team driven by excellence, the unwavering objective when providing specific, effective responses to the needs of our young patients and their families.

Bruno Dallapiccola Scientific Director
Massimiliano Raponi Healthcare Director
The number of children with complex chronic diseases is increasing in all industrialised nations, specifically because modern medicine is enabling the survival, often to adult age, of a large number of children who, until a few years ago, were dying in the first days, months or years of life. Medicine is currently transforming rapidly fatal diseases into chronic diseases, and does not always provide a complete cure, with the exception of certain cases in which innovative treatments (such as transplants) represent a successful strategy.

The complexity of these patients derives from dependence on technological systems, such as devices for assisted ventilation, and the need for a large number of drugs, frequent and prolonged hospitalisation and home health services. Because of all these needs, children and families are encountering a ‘new poverty’ that, in most cases, is actually real poverty caused by the financial burden of the illness, which affects not only the child but its entire family, including parents and siblings.

Medical care of these children invariably requires the involvement of numerous specialists who, in order to obtain effective results, must work as a team and are coordinated – in order to ensure that the child and its family remain the focus of their actions, in terms of the physical, spiritual, psychological and social integrity of the person of the patient – usually by a paediatrician as part of an integrated multispecialist and multiprofessional approach. On the basis of an analysis performed in our Hospital, patients with complex chronic conditions represented approximately 27% of patients treated in 2014.

The need to provide appropriate care for these patients should drive hospitals to rely on evidence-based medicine, which development has made it possible to understand that, in taking decisions about the management of the individual patient and in assessing the effectiveness of each therapy (a treatment is effective if improvements in the health of a patient can be expected after it has been provided), it is essential to make use of the best available evidence as to avoid the application of unnecessary treatments that can sometimes represent a risk for the health of the patient, and certainly represent a waste of resources. In addition, the implementation of guidelines, clinical protocols and peer review systems, in recent years the OPBG has used an additional tool that promotes efficiency and appropriateness in clinical procedures, known in the literature as the ‘clinical pathway’.

The clinical pathway can be defined as an ‘instrument used to coordinate the treatment of the patient in terms of time and among various facilities. It reflects the objectives that clinicians and patients are required to achieve, as suggested by an optimal sequence of interventions defined over time, structured to achieve these objectives as efficiently as possible’ (Rohrbach, 1999)

A fundamental aspect of the clinical pathway is that it requires a preliminary determination, for each type of patient, of the corresponding optimal reference clinical and organisational pathway. At the same time, it provides a tool that can be used to measure the deviation from the optimal clinical pathway that has actually occurred in the treatment of patients. The clinical pathway is a multidisciplinary treatment plan, the content of which is based on Evidence-Based Medicine, which is used to determine both the treatment objectives relating to a specific clinical category of patients and the actions, in terms of an ordered sequence over time, that should be applied to achieve the above-mentioned objectives, by the medical professionals taking part in the treatment of that type of patients. The identification of ordered sequences of actions that must be implemented by the professionals involved in the clinical pathway makes it possible to reduce unjustified variability in treatments (the degree to which the actions actually performed deviate from those recommended must be demonstrated and justified) and makes it possible to determine the costs and schedule the resources to be used for treatment of a specific category of patients.

In general terms, the Hospital’s experience has shown that the development of a clinical pathway should be based on a participative methodology, in which the group of clinical experts agrees the entire care pathway for a specific type of patient on the basis of the available scientific evidence, integrating the care requirements with the requirements of patients and their families.

2014 Care Activities

<table>
<thead>
<tr>
<th></th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
<th>% Diff.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beds</td>
<td>607</td>
<td>607</td>
<td>607</td>
<td>0%</td>
</tr>
<tr>
<td>No of admissions</td>
<td>26,319</td>
<td>26,770</td>
<td>27,342</td>
<td>4%</td>
</tr>
<tr>
<td>of which Rehabilitation</td>
<td>589</td>
<td>606</td>
<td>626</td>
<td>6%</td>
</tr>
<tr>
<td>A&amp;E</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average weight</td>
<td>1.05</td>
<td>1.04</td>
<td>1.02</td>
<td>-3%</td>
</tr>
<tr>
<td>Average length of stay</td>
<td>6.31</td>
<td>6.06</td>
<td>6.07</td>
<td>-4%</td>
</tr>
<tr>
<td>REHABILITATION</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average length of stay</td>
<td>28.41</td>
<td>26.90</td>
<td>27.59</td>
<td>-3%</td>
</tr>
<tr>
<td>OUTPATIENT SURGERY</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cases</td>
<td>5,744</td>
<td>5,400</td>
<td>5,493</td>
<td>-1%</td>
</tr>
<tr>
<td>A&amp;E</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Visits</td>
<td>70,911</td>
<td>72,744</td>
<td>77,232</td>
<td>9%</td>
</tr>
<tr>
<td>OUTPATIENT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Procedures</td>
<td>1,139,450</td>
<td>1,411,517</td>
<td>1,589,080</td>
<td>39%</td>
</tr>
<tr>
<td>OPERATING ACTIVITY</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgical procedures</td>
<td>25,613</td>
<td>28,131</td>
<td>28,300</td>
<td>10%</td>
</tr>
<tr>
<td>TRANSPLANTS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transplants</td>
<td>298</td>
<td>324</td>
<td>314</td>
<td>5%</td>
</tr>
</tbody>
</table>

The above overview shows the changes in the principal indicators for activities performed by the Hospital in the three-year period 2012-2014. In 2014, the Hospital consolidated the flows of ordinary admissions developed over the preceding three-year period. As for each operating year, the strategic objective was focused, as far as possible, on the use of ordinary admissions for patients with complex conditions that cannot be treated using other systems and models.

There is a continued downward trend in admissions for day hospital services, which benefited outpatient activities, on the basis of organisational models that give priority to ensuring clinical appropriateness, in accordance with the regional legislation, and have made it possible to transfer a significant portion of services dispensed in the day hospital to lower-level treatment regimes, with the same effectiveness of care.

In terms of this aspect, outpatient surgery has demonstrated its excellence through the volume of patients (+2% compared to 2013), which places the Hospital in a leading position nationally in terms of paediatric cases treated.
The trend of ordinary admissions for neurorehabilitation, at the Palidoro and Santa Marinella facilities, have seen constant growth over recent years. In 2014, we confirmed our high levels of transplant-related productivity: kidney transplants increased by 32%, bone marrow transplants by 11%, heart transplants by 50% and liver transplants were in line with the figures for 2013. We have also consolidated activities involving transplanting of organs from living donors, which represent 43% of liver transplants and 20% of kidney transplants.

In terms of attracting patients from regions other than Lazio, in 2014, 28% of patients at the OPBG admitted under the ordinary admissions regime came from other regions, and, on average, the complexity of these cases was approximately 51% higher than the average of patients from Lazio.

Foreign patients also represented a significant portion of the total numbers of cases treated at the OPBG. In particular, in 2014, foreign patients represented 12% of ordinary admissions. The level of complexity associated with foreign patients in 2014 was 48% higher than for patients from Lazio.

Analysis of the ability to attract cases from outside the Lazio Region by admission type shows that, in the last three years of activity, the hospital has maintained a steady ratio of cases from outside the region in the total number of acute ordinary admissions. Analysis of admissions by region of origin shows that patients came predominantly from central and southern areas, and in particular Campania (25%), Puglia (14%) and Calabria (14%) (figure 2).

An analysis of severity and area of origin shows that, in 2014, patients from Northern Italy with extreme or major complexity represented 16% of the total, while in the Central areas (excluding Lazio), this was 12% of the total and in the South it was 14% of the total (figure 3).

In 2014, the numbers of foreign patients treated by the Hospital as ordinary admissions increased (+2.2%) compared to the figures for 2013. We can however see a decrease in the numbers of day admissions compared to 2013 (-9.2%), which is consistent with figures throughout the Hospital.

### Table 1. Change in OPBG transplant activity. 2007-2014 Years

<table>
<thead>
<tr>
<th>Transplants</th>
<th>2007</th>
<th>2008</th>
<th>2009</th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
<th>2013</th>
<th>2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kidney Transplant</td>
<td>23</td>
<td>10</td>
<td>24</td>
<td>13</td>
<td>16</td>
<td>17</td>
<td>19</td>
<td>25</td>
</tr>
<tr>
<td>from living donors</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>7</td>
<td>5</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Heart Transplant</td>
<td>12</td>
<td>12</td>
<td>15</td>
<td>9</td>
<td>10</td>
<td>14</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Artificial Heart Transplant</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>11</td>
<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Lung Transplant</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>3</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Liver Transplant</td>
<td>-</td>
<td>3</td>
<td>15</td>
<td>16</td>
<td>15</td>
<td>17</td>
<td>23</td>
<td>22</td>
</tr>
<tr>
<td>from living donors</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Intestinal Transplant</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Autologous Bone Marrow Transplant</td>
<td>17</td>
<td>31</td>
<td>16</td>
<td>25</td>
<td>28</td>
<td>29</td>
<td>33</td>
<td>55</td>
</tr>
<tr>
<td>Allogeneic Bone Marrow Transplant</td>
<td>9</td>
<td>15</td>
<td>16</td>
<td>82</td>
<td>96</td>
<td>108</td>
<td>114</td>
<td>108</td>
</tr>
<tr>
<td>Heart Transplant</td>
<td>12</td>
<td>12</td>
<td>15</td>
<td>9</td>
<td>10</td>
<td>14</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Artificial Heart Transplant</td>
<td>-</td>
<td>-</td>
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<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Lung Transplant</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Liver Transplant</td>
<td>-</td>
<td>3</td>
<td>15</td>
<td>16</td>
<td>15</td>
<td>17</td>
<td>23</td>
<td>22</td>
</tr>
<tr>
<td>from living donors</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Intestinal Transplant</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Autologous Bone Marrow Transplant</td>
<td>17</td>
<td>31</td>
<td>16</td>
<td>25</td>
<td>28</td>
<td>29</td>
<td>33</td>
<td>55</td>
</tr>
<tr>
<td>Allogeneic Bone Marrow Transplant</td>
<td>9</td>
<td>15</td>
<td>16</td>
<td>82</td>
<td>96</td>
<td>108</td>
<td>114</td>
<td>108</td>
</tr>
<tr>
<td>Heart Transplant</td>
<td>12</td>
<td>12</td>
<td>15</td>
<td>9</td>
<td>10</td>
<td>14</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Artificial Heart Transplant</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
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<td>-</td>
</tr>
<tr>
<td>Lung Transplant</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Liver Transplant</td>
<td>-</td>
<td>3</td>
<td>15</td>
<td>16</td>
<td>15</td>
<td>17</td>
<td>23</td>
<td>22</td>
</tr>
<tr>
<td>from living donors</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>2</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>Intestinal Transplant</td>
<td>-</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

In 2014, the numbers of foreign patients treated by the Hospital as ordinary admissions increased (+2.2%) compared to the figures for 2013. We can however see a decrease in the numbers of day admissions compared to 2013 (-9.2%), which is consistent with figures throughout the Hospital.
Improving the quality of treatment is a central theme in healthcare, so as to reduce the risk of errors, adverse events and unsatisfactory outcomes. In line with its mission, the OPBG places patients and their families at the very heart of the care model, and ensuring the safety of treatments is therefore a central aspect in the Hospital’s activities.

Risk of Infection: prevention of the intra-hospital circulation of antibiotic resistant microorganisms

The spread of antibiotic-resistant bacteria represents an important public health problem, especially for Italy, which is one of the countries within Europe that is most affected by the phenomenon of antibiotic resistance. In hospital paediatrics, the adoption of good practices for the prevention and control of bacteria that have developed resistance to antibiotics is particularly important in limiting the risk of spread within vulnerable populations, such as newborns or patients with oncohaematological conditions. At the OPBG, all patients with infections or colonization by germs that are multiresistant to antibiotics are cared for through the adoption, in addition to standard precautions, of contact precautions (involving the use of gowns, gloves and antiseptic handwashing). In recent years, there has also been significant spread within Italy of gram-negative bacteria belonging to the family of enterobacteria (Klebsiella pneumoniae) and Pseudomonas aeruginosa, which are resistant to carbapenems, the basic drugs used to treat serious infections caused by multi-resistant bacteria. These gram-negative bacteria resistant to carbapenems are generally found in the intestine and in the faeces and are transmitted by person-to-person contact. Since 2012, all cases where gram-negative germs resistant to carbapenems are isolated are actively notified by Microbiology to the Infection Control Committee, which verifies that appropriate contact precautions are applied. The Neonatologists and Oncohaematology Departments, which admit the patients with the greatest risk of invasive infections such as bacteremia, also apply active surveillance of intestinal carriers of gram-negative germs that are resistant to carbapenems. The adoption of all these actions has made it possible to reduce the frequency of microorganisms that are multiresistant to antibiotics (methicillin-resistant staphylococcus aureus, gram-negative bacteria resistant to carbapenems and enterococci resistant to vancomycin). The proportion of these microorganisms in the total isolated using antibiograms at the OPBG has fallen from 35% in 2011 to 6.4% in 2014.

Handover

The point of handover of clinical information between the various professionals involved in the diagnostic and care pathway for patients (doctors, nurses and other medical professionals) is particularly important in guaranteeing the quality and safety of treatment. In 2014, the OPBG drafted a protocol providing instructions for handovers. In all situations in which verbal clinical information is handed over between operators, as happens for example during shift changes, the SBAR communication method is applied. This method involves a summary illustration of the Situation, Background, Assessment and Recommendations (SBAR) for the patients. In addition, during handovers between doctors from Operational Units and night shifts or holiday shifts, the doctor going off-shift verbally informs the doctor coming on-shift of the presence in the Unit of any patients who are not clinical stable, and stable patients with clinically serious problems (such as emergency admissions requiring day hospitalisation following surgical or diagnostic procedures). This information is entered in the bed management software used in the Hospital.

Response to intra-hospital emergencies

In Operational Units with non-intensive admissions, clinical emergencies that require cardiopulmonary resuscitation are rare, but can have serious outcomes. In 2014, the OPBG further reinforced the response capacity of its personnel in such emergencies, both to enable early identification of patients at risk of clinical deterioration and to ensure timely intervention where necessary. To ensure timely identification of at-risk patients and to implement the necessary preventive actions, all non-intensive Operational Units have adopted the BedsidePEWS early warning system. This is an early warning system made up of a risk score based on vital signs and certain care recommendations that vary according to the score. The BedsidePEWS score is also used in medical and nursing handovers to indicate the patients at greatest risk of clinical deterioration. In the event of an emergency, all personnel are trained in basic cardiopulmonary support; in each Operational Unit, there is also a designated reference resuscitation officer who can act if advanced support is required. In 2014, the Hospital also initiated a training approach focused on knowledge of internal resources for management of emergencies, drills of technical skills and on-site drills according to the Crisis Resource Management (CRM) method.

Morbidity and Mortality Conference

Morbidity and mortality conferences (MMMC) are periodic meetings in which the healthcare personnel hold a joint discussion about the system elements that could have contributed to the occurrence of a critical situation during diagnosis and treatment, in order to implement improvements in the quality of care. Developed at Massachusetts General Hospital in 1995, MMCCs are very widespread within the English-speaking world. At the OPBG, they have been conducted by medical personnel since 2007, and by nursing personnel since 2012. In 2014, on the basis of our understanding of the importance of integrating the various professional figures who support admitted patients, MMCCs have involved all care personnel.
The keywords that have characterised 2014 for nursing personnel and medical professionals have been Integration, Expertise and Innovation, with a view to maximising openness and involvement of children and families in line with a holistic view of care focussed on meeting their care needs.

Family-Centred Care, a specific approach

In 2014, we also continued exploration of the values and principles associated with family-centred care (FCC) in various situations. We concluded the multicentre study coordinated by the OPBG, aimed at validating the Italian version of a questionnaire to explore the degree of satisfaction and the experience of parents of newborns discharged from a Neonatal Intensive Care Unit (NICU). The study involved nine Italian hospitals and the participation of the parents of 162 newborns. The questionnaire, referred to as Empathic-N, is a methodologically rigorous tool, which brings together information about the various areas making up FCC: information, care and treatment, participation by parents, organisation and professional attitude. A similar version has also been developed for sub-intensive neonatal areas (Empathic-SN). The Italian neonatology sector will therefore have an instrument that can be used for systematic and detailed evaluation of parent satisfaction. In general in the various centres involved, the responses from parents have provided positive feedback about the various areas (Likert scale from 0 to 6) and the results correlate positively with the general opinions reported to doctors and nurses (from 1 to 10), and to experience in general (We would recommend this NICU to anyone who is in a situation similar to ours – Q58. If we were in a similar situation again, we would go to this NICU – Q59). The open responses provided by the parents reveal certain basic conceptual categories: the emotional involvement of the parents, the need for information, the need for appropriate facilities and services, the central nature of the relationship with the operators, and the quality of communication.

Evaluation of Post-Operative pain using an app at home

Thanks to the research project on ‘Innovative paediatric surgery models: post-discharge safety and exploration of new methods for evaluating pain’, conducted at the OPBG Day Surgery unit, we have begun training parents in the use of pain evaluation scales following surgery and made available in the form of an app to be used for home evaluation, with registration of data using an IT platform displayed constantly by a nurse. The primary objective of this activity is to guarantee safe and effective management of post-operative pain at home by means of family empowerment.

The ‘Guiding Value’ of the project was therefore to facilitate the involvement and participation of parents in treatment plans and to provide families with the tools to recognise and evaluate pain to ensure greater protection for the children concerned. Trained, informed parents will know how to treat and manage the health problems of the children that we support in hospital and then entrust, following discharge, to the care of their parents.

The project has been implemented through the following phases:

- Training of personnel
- Development of an app for the evaluation of pain
- Training of family members in how to determine pain
- Evaluation of satisfaction: out of 547 patients enrolled, none of the parents refused to use the app, and they all showed real interest and appreciated the involvement and the training provided. The level of satisfaction among the parents who used the application at home was very high: 85% of parents were very satisfied and 15% were satisfied.

Training

On-site drills and Crisis Resource Management (CRM)

Crisis Resource Management is a simulation method used to run drills not only of technical skills but also of non-technical skills, which are believed to be the primary cause of health system errors. Non-technical skills valuable in medical environments include leadership, communication within the team, understanding and use of resources, awareness of the situation and setting errors. The advantage of this approach is the realism of the setting, which includes the facility, the equipment available and the team involved in the drill; the staff perform the drill using the resources that they would have available in a real work situation, with the added value of being able to reflect on their own actions in a protected environment, without any risks for themselves or the patient.

Training in hospital cardiopulmonary resuscitation techniques

In order to guarantee optimal safety for our small patients, the hospital ensures a ‘Particular focus on refresher training in basic and advanced cardiopulmonary resuscitation techniques. The basic cardiopulmonary resuscitation is intended for all medical operators in direct contact with patients, except for specialist doctors in critical areas operating in clinical activities. The course is repeated every two years.’

All new operators who meet the requirements of the Medical policies must be trained in cardiopulmonary resuscitation techniques. The validity of certification is 24 months and retraining must be scheduled within one month of expiry to meet the JCI standard (SQE.8.1).

Training is provided by cooperation with the following:

- The PBLSD/Simeup Training Centre;
- The PALS American Heart Association (AHA)/Sim-courses;
- The AHA ITc for AHA BLS courses

In addition to these activities, 9 free PBLSD are provided for parents, with 4 of the 24 spots in Rome and 5 of the 20 spots in Paldoro (total 196).

Nursing and Training Activities

The Hospital Counsellors have put together a Support Group, defined by the WHO as ‘all of the measures adopted by non-professional figures to promote, maintain or recover health, understood as being the complete physical, psychological and social well-being of a community’. The purpose of this group is to exchange experiences, tell individual stories, listen; meet people who are dealing with the same issues and have found valuable methods of coping and managing, which can provide hope and a sense of optimism. The participation of parents with children admitted or who have been discharged from the Operational Units included in the project is voluntary and the number of participants in the Group can vary up to about ten individuals. Where a parent who speaks a foreign language takes part in this group, a Cultural Mediator is provided.

The Hospital’s School has been enriched through the participation of the prestigious Liceo Virgilio high school, in addition to the scholastic organisations that have already provided a complete curriculum at the Hospital’s three sites, making it possible for more than 2,800 hospitalised children to make use of educational services.

Family-Centred Care, a specific approach

In 2014, we also continued exploration of the values and principles associated with family-centred care (FCC) in various situations. We concluded the multicentre study coordinated by the OPBG, aimed at validating the Italian version of a questionnaire to explore the degree of satisfaction and the experience of parents of newborns discharged from a Neonatal Intensive Care Unit (NICU). The study involved nine Italian hospitals and the participation of the parents of 162 newborns. The questionnaire, referred to as Empathic-N, is a methodologically rigorous tool, which brings together information about the various areas making up FCC: information, care and treatment, participation by parents, organisation and professional attitude. A similar version has also been developed for sub-intensive neonatal areas (Empathic-SN). The Italian neonatology sector will therefore have an instrument that can be used for systematic and detailed evaluation of parent satisfaction. In general in the various centres involved, the responses from parents have provided positive feedback about the various areas (Likert scale from 0 to 6) and the results correlate positively with the general opinions reported to doctors and nurses (from 1 to 10), and to experience in general (We would recommend this NICU to anyone who is in a situation similar to ours – Q58. If we were in a similar situation again, we would go to this NICU – Q59). The open responses provided by the parents reveal certain basic conceptual categories: the emotional involvement of the parents, the need for information, the need for appropriate facilities and services, the central nature of the relationship with the operators, and the quality of communication.

Evaluation of Post-Operative pain using an app at home

Thanks to the research project on ‘Innovative paediatric surgery models: post-discharge safety and exploration of new methods for evaluating pain’, conducted at the OPBG Day Surgery unit, we have begun training parents in the use of pain evaluation scales following surgery developed and made available in the form of an app to be used for home evaluation, with registration of data using an IT platform displayed constantly by a nurse. The primary objective of this activity is to guarantee safe and effective management of post-operative pain at home by means of family empowerment.

The ‘Guiding Value’ of the project was therefore to facilitate the involvement and participation of parents in treatment plans and to provide families with the tools to recognise and evaluate pain to ensure greater protection for the children concerned. Trained, informed parents will know how to treat and manage the health problems of the children that we support in hospital and then entrust, following discharge, to the care of their parents.

The project has been implemented through the following phases:

- Training of personnel
- Development of an app for the evaluation of pain
- Training of family members in how to determine pain
- Evaluation of satisfaction: out of 547 patients enrolled, none of the parents refused to use the app, and they all showed real interest and appreciated the involvement and the training provided. The level of satisfaction among the parents who used the application at home was very high: 85% of parents were very satisfied and 15% were satisfied.

Training

On-site drills and Crisis Resource Management (CRM)

Crisis Resource Management is a simulation method used to run drills not only of technical skills but also of non-technical skills, which are believed to be the primary cause of health system errors. Non-technical skills valuable in medical environments include leadership, communication within the team, understanding and use of resources, awareness of the situation and setting errors. The advantage of this approach is the realism of the setting, which includes the facility, the equipment available and the team involved in the drill; the staff perform the drill using the resources that they would have available in a real work situation, with the added value of being able to reflect on their own actions in a protected environment, without any risks for themselves or the patient.

Training in hospital cardiopulmonary resuscitation techniques

In order to guarantee optimal safety for our small patients, the hospital ensures a ‘Particular focus on refresher training in basic and advanced cardiopulmonary resuscitation techniques. The basic cardiopulmonary resuscitation is intended for all medical operators in direct contact with patients, except for specialist doctors in critical areas operating in clinical activities. The course is repeated every two years.’

All new operators who meet the requirements of the Medical policies must be trained in cardiopulmonary resuscitation techniques. The validity of certification is 24 months and retraining must be scheduled within one month of expiry to meet the JCI standard (SQE.8.1).

Training is provided by cooperation with the following:

- The PBLSD/Simeup Training Centre;
- The PALS American Heart Association (AHA)/Sim-courses;
- The AHA ITc for AHA BLS courses

In addition to these activities, 9 free PBLSD are provided for parents, with 4 of the 24 spots in Rome and 5 of the 20 spots in Paldoro (total 196).
The following is a summary of the areas of excellence and the innovative care activities that characterised the activities of the various departments in 2014.

Surgery Department

The Audiology and Otology Operative Unit is a regional centre for screening of neonatal deafness. In 2014, the Unit performed the largest number of tests of brain stem auditory evoked potentials in Lazio, with more than 300 during spontaneous sleep, sedation and general anaesthesia, along with 32 operations, among a total of 200 complex surgery interventions, to fit cochlear implants for treatment of childhood deafness.

The care innovations implemented include the following:

- First implant in Europe of a new model of transcutaneous bone conduction implant (Baha Attract) in paediatric age;
- Creation of a focus group to provide dedicated support for parents of deaf children who are candidates for cochlear implants, providing monthly meetings among parents, doctors and audiometrist technicians, in cooperation with a psychologist specialised in clinical psychology.

The Digestive Endoscopic Surgery Operative Unit achieved outstanding levels in 2014 in the performance of the recently developed endoscopic surgical procedures using the therapeutic endoscopy technique, and obtained recognition of its international potential for development of an oesophageal stent, dynamic oesophageal stent OPBG, 2014 confirmed the role of the OPBG as a primary centre in Italy for paediatric liver transplants, also confirming its position in the leading national facility for activities involving transplants from living donors (paediatric liver transplants).

The activities of the General and Thoracic Surgery Operative Unit were characterised by an increase in surgical procedures, because of the need to manage oncological and thoracic conditions, which required the medical and nursing teams to adhere to the standards relating to ‘timeframes for diagnosis and surgical treatment’ within 48 hours following arrival, as envisaged by our procedures.

This Unit continued its collaboration with Interventional Radiology, through which it further fine-tuned protocols for minimally invasive treatment of vascular lesions (general angioma and lymphangioma), solid mass biopsies (neoplasia) with guidance by ultrasound or haemodynamic, with the result that time to diagnosis can be shortened and treatment times accelerated in this case also.

The Maxillofacial Plastic Surgery Operative Unit has introduced and used the following in clinical and surgical practice:

- New devices for treatment of congenital giant melanoctye nevi such as: omeprazole expanders and skin approximators.
- New devices and equipment for treatment of ‘difficult’ wounds, such as:
  - Negative pressure therapy;
  - Dermal regeneration matrices;
  - Decellularised dermis;
  - Cell therapy using platelet gel and centrifuged adipocytes.
- New procedures such as: regenerative medicine and surgery for treatment of rehabilitative and post-traumatic conditions;
- New devices and equipment such as ‘piezosurgery’ for treatment of rehabilitative and maxillofacial conditions;
- New techniques for microsurgical muscle dissection to correct labiopalatoschisis.

An outpatient service for prenatal diagnosis of labiopala- toschisis was also created, which accommodates pregnant women and newborns with labiopalatoschisis, and for which the multidisciplinary therapeutic pathway has been defined.

The Hepatology, Gastroenterology and Nutrition Oper- active Unit saw a further increase in the number of liver transplants (24 transplants, including eight from living donors). 84% of transplants were performed on patients who were not from the Lazio Region, and 16% were per- formed on non-Italian patients. For all transplants, a fa- vourable outcome was confirmed during follow up. The Unit also performed the first transplant in the world for a new metabolic indication (ethylmalonic aciduria).

The Hepatometabolic Diseases Operative Unit made the transition from research to clinical practice one of its car- dinal objectives. In this regard, it is currently involved in two ‘on time’ pharmacological trials with DHA and vitamin D and with choline for the treatment of steato- hepatitis, and especially hepatic fibrosis. It has also vali- dated two markers of hepatic damage in clinical practice (cathepsin D and bilirubin acid) published recently as part of a programme of international cooperation.

The clinical and organisational innovations that have characterised the activities of the Gastroenterology Operative Unit in 2014 include the following:

- Performance of the first artificial cornea transplant using a Boston keratoprosthesis in a paediatric patient;
- Opening of the coordinated ocular oncology outpatient clinic in which an ophtalmologist and an on- cologist examine the patient together and define the corresponding therapeutic and treatment pathways;
- Conclusion of an agreement with the Vatican Muse- ums for joint activity as part of the rehabilitation of patients associated with the Santa Martina Rose visual re- habilitation outpatient unit.

At the Oral Surgery Operative Unit, 2014 saw the intro- duction of dental trache to optimise management of ini- tial patient visits, with implementation of an algorithm to determine if treatment is provided at the right time on the basis of priority criteria. It should also be noted that the Unit has implemented the strategy relating to the use of conscious sedation using nitrous oxide for outpatient treatment.

In 2014, the Orthopaedics Operative Unit saw an in- crease in cases of scoliosis (initial implant), from 90 to 120. Total numbers of spinal surgeries, including all other cases except initial implants for scoliosis, increased from 130 to 150. The unit continued with application of mag- netic bars in the treatment of severe cases of childhood scoliosis, with five additional implants in 2014, meaning that OPBG has the most paediatric cases in Italy, a total of 16. In the past year, the ENT Operative Unit con- tinued a collaborative relationship with neurosurgery for conditions affecting the base of skull, providing its neu- rosurgery colleagues with the option of approaching the base of skull by means of nasal endoscopy. It set up a level II outpatient service for sleep-disordered breathing relat- ing to ENT, with the involvement of the Oral Surgery and Bronchopulmonary units.

Admissions for adenotonsillectomy, in line with regional criteria of clinical appropriateness, have been transferred from ordinary admissions to one-day surgery. The In- terventional Radiology Operative Unit has begun coop- eration with Nephrology for the treatment of tuberous sclerosis through the commencement of multidisciplinary consulting on Day Hospital activities for this condition.

Imaging Department

For approximately two years, the Department has been introducing morphological and dynamic MRI analysis for palatine assessment in patients undergoing surgery for labiopalatoschisis (cleft lip and palate) and in patients with clinical symptoms of submucosal cleft. The results of the analyses, which would otherwise be obtained using invasive techniques such as rhinoscopy or videofluo- scopy, which use ionising radiation, are excellent, and show a satisfactory correlation with the clinical data. The exami- nation is now included in the analysis protocols for these patients, although it has the limitation of being a long, complex analysis that requires cooperation between the patient and the radiology team.

Laboratories Department

2014 marked an important moment for the Laboratories Department, because the transfer of the research labora- tories to San Paolo presented the possibility of moving the analysis laboratories to the areas vacated and planning their reorganisation: consolidation, centralisation, unifi- cation of analytical processes through the use of transverse platforms, increased focus on automation. The significant care innovations include the structuring of the Parasi- tology Operative Unit as a Tropical Medical Unit, along the lines of the London School of Hygiene & Tropical Medicine (LSHTM), where most of the operators have attended courses and advanced courses in the Department introduced very-high-sensitivity and -specificity rapid testing (leishmanina and malaria), replacing the costly IFA methods and included in routine lysophosphatidyl end-point PCR for molecular speciation.

The microbiology laboratory introduced MALDI-TOF technology, for rapid identification of pathogens directly

Department of Emergency Admissions and Anaesthesiology - Resuscitation - Operating Rooms

Transport of Paediatric Patients subject to Respiratory ECMO Treatment. ECMO (extracorporeal membrane oxygenation) is an extracorporeal circulation technique that enables normal respiration (inhalation of O2 and ex- hilation of CO2); it is used in cases of potentially ‘re- versible’ acute respiratory or cardiorespiratory failure that do not respond to conventional resuscitation treatments (mechanical ventilation).

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from a positive blood culture vials, reduced turn-around time (TAT) in the diagnosis of sepsis, and introduced the first software for prescription appropriateness. The cytogenetics and molecular genetics laboratory has extended the standard range of genetic tests offered through the use of next-generation sequencing (NGS), and has thus broadened its role, creating a network within the Hospital involving participation by all specialisations, received samples from foreign countries, and formalized the performance of genetic tests in countries with limited resources and a high incidence of hereditary illnesses linked to consanguinity.

The anatomical pathology laboratory has been substantially focused on the diagnosis of genetic diseases with hepatic expression and is mapping the geographical and ethnic distribution of a new illness, ‘hereditary hypophosphatetbrinogenemia with storage in the liver’. Diagnostic work has also focused on oncology conditions, with particular attention to the tissue demonstration of altered expressions of receptors and molecules, intended to define prognostic criteria and targeted therapies.

The Arhythmology unit has installed the Univu Module on the AFETO 3 three-dimensional system for integration of fluoroscopic images with 3D electroanatomical maps for radiofrequency catheter ablation, with minimal use of fluoroscopy. In addition, the performance of Cryo procedures using three-dimensional mapping has made it possible to reduce or indeed eliminate use of fluoroscopy. The Unit is also performing implants of microscopic subcutaneous loop recorders that can be used in children for home-based monitoring of arrhythmias.

In the Cardiac Surgery Operative Unit, the treatment of very-low-weight patients symptomatic of isolated mitral conditions or mitral conditions associated with Shone’s syndrome is feasible, because it is not possible to repair the valve damage and there is no appropriate replacement device. The patients undergoing mitral valve replacement using off-label surgical implanting of Medtronic Melody valve stents (according to the technique described by Abdullah et al.) included two newborns with complex mitral conditions weighing less than 3 kg. Both procedures were performed successfully and the patients currently represent the lowest weights for this procedure ever recorded in the literature. The principal innovations introduced in cardiodiagnoses include the use of cardiac NMR using a magnet located inside the Medical-Surgical Department of Paediatric Cardiology (DMCCP), which currently represents the only Italian paediatric application, and the now routine use of three-dimensional methods in paediatric ultrasound, which is currently used in only a small number of paediatric cardiology and cardiosurgery centres.

Percutaneous treatment of low-weight patients represents a new challenge for paediatric haemodynamics. The presence of a wide ductus arteriosus causes excessive pulmonary inflow and severe overload of the left ventricle, which exposes the newborn to the risk of respiratory infection, limited growth and the risk of intestinal necrosis resulting from diastolic steal. In cases where pharmacological treatment to close the ductus arteriosus cannot be implemented, such as cases with comorbidities, or is ineffective, percutaneous treatment is a valid alternative to surgery. The development of materials technologies has enabled the use of mechanisms designed to close the ductus arteriosus (Arterial Duct Occluder, ADO) even in low-weight patients. At the OPBG, ten newborns/infants weighing less than 3 kg and suffering from serious comorbidities have undergone percutaneous closure of the ductus arteriosus. Follow-up has shown a satisfactory result, with reduction of diuretic treatment to the point of suspension, reduction in the dimensions of the left ventricle and an improvement in growth trend. No vascular complications have been recorded.

In Cardiosurgical Paediatric Intensive Care Unit, a project was launched to develop an integrated monitoring system able to gather all physiological parameters deriving from the various sources and use mathematical models to estimate new derived parameters that can be used to support clinical and therapeutic decisions. The advanced monitoring system is made up of two applications:

• a digital model of the cardiovascular system, which acquires haemodynamic data to simulate clinical conditions and predict the effect of specific therapies
• an IT application that uses a dynamic Bayesian network to estimate the probability that a particular event will occur.

A new haemodialysis application for newborns has been implemented by means of the use of a new dialysis system, CARPEDIEM, which has been designed and developed for the specific purpose of treating patients weighing less than 10 kg. The system has very high accuracy, and it is possible to identify balancing errors relating to weight during treatment. Heat dispersion has been reduced to a minimum through the extreme reduction in the haematic surface area exposed.

Medical-Surgical Department of Paediatric Cardiology

Department of Paediatric Medicine

Allergology Operative Unit

• Performance of an initial IgE apheresis procedure in paediatrics on a child with severe food allergies;
• creation of an outpatient clinic dedicated to immunological therapy in allergic rhinitis, with active provision of specific immune therapy options at prices below market levels.

Bronchopneumonia Operative Unit

• Creation of an outpatient clinic dedicated to chronic pulmonary diseases and primary ciliary dyskinesia;
• development of an innovative care programme for congenital central hypoventilation syndrome (CCHS, or Ondine’s syndrome) with application of non-invasive ventilation for patients suffering from poly-ALD mutation and decannulation of patients of pre-adolescent age, with commencement of ventilation by mask, in order to improve quality of life and acceptance of the condition;
• creation of an outpatient clinic dedicated to sleep disorders.

Dermatology Operative Unit

• Total treatment of patients with ichthyosis: multidisciplinary and medical approach in collaboration with the UNITI parents association, the only Italian centre offering total management of ichthyosis in children;
• coordination of a humanitarian project for Syrian refugees in Lebanon and training of nursing personnel from Caritas Libano.

Food Education Operative Unit

• Introduction of specific day hospitals for multidisciplinary treatment of obese adolescents, with strengthened motivation for the approach by means of the ‘on-line diary’;
• development of specific formats for food education programmes to be implemented in schools.

Cystic Fibrosis Operative Unit

• Application of a specific protocol for recognition and follow-up of classic late-onset forms of cystic fibrosis, arthropical forms and single-organ CFTR-related conditions;
• study of the ‘lung clearance index’ for early diagnosis of parenchymal ventilatory dishomogeneity;
• implementation of an interventional diagnostic-therapeutic protocol, with the ENT Operative Unit, for the prevention and treatment of bone erosion caused by chronic infections of the paranasal sinuses; identification and early treatment of multi-drug-resistant (MDR) germs present in the paranasal sinuses.

Rare Diseases Operative Unit

• Development of a national network for diagnosis and treatment within territory of residence of patients suffering from undiagnosed rare diseases.

Metabolic Conditions Operative Unit

• Implementation of a programme for liver transplants and haematopoietic stem cell transplants in patients with metabolic diseases.

Department of Paediatric Intensive Care Unit

• Implementation of a centre for children with disabilities for integrated multispecialty management of chronic and high-complexity patients with disabilities.

Rheumatology Operative Unit

• Implementation of a programme for the use of innovative biological drugs for treatment of juvenile idiopathic arthritis;
• implementation of a centre for diagnosis and innovative treatment of new autoinflammatory syndromes with recurrent fever;
• coordination of international clinical trials on innovative biological drugs, also involving the rheumatology research laboratory, focused on analysis of the mechanisms of inflammation and identification of new therapeutic targets.

Department of Surgical Neonatology

Strengthening of neonatal intensive care and implementation of ‘vertical – transversive’ activities in neonatal semi-intensive care. Start-up of a new organisational model for neonatal sub-intensive care to promote the flow of patients from intensive care to semi-intensive care (medical and surgical).

In utero treatment. Creation of a multidisciplinary in-ter-hospital team for performance of in utero therapeutic procedures. The following have been performed: three tracheal plucks (ballonni); three thoracic-amiotic drain-age procedures.

Minimal access surgery. Neonatal minimal access surgery activities have been progressively strengthened. 22 procedures were performed over the course of the year, involving 16 laparoscopic and seven thoracoscopic procedures.
Prenatal diagnosis and counselling. Increase of about 50% in prenatal counselling (20 additional sessions/month).

Awake surgery: Increased number of procedures performed with the patient awake, indicated in newborns with minor conditions: inguinal hernia and pyloric stenosis. More than 35 cases in total treated successfully since 2013.

Non-Operative Room Anaesthesia (NORA): NORA was performed for surgery indication with drugs systemically adminis- tered intravenously only to induce sleep other than those used for general anaesthesia, and thus has clear benefits for patients associated with reduced post-operative admission in intensive care procedures, mostly septic biopsies (18 cases) and retinopathy of prematurity (12 cases).

Short bowel syndrome (SBS). The unit has continued its activities, in cooperation with the Surgical Department, on classification and treatment of SBS/intestinal failure, to enable a recovery of digestive self-sufficiency, including through the use of advanced, innovative surgical techniques. Throughout 2014, 13 procedures were performed for treatment of Short bowel syndrome (SBS), including one spiral lengthening (SILT) and two longitudinal lengthenings (LIIT), with intestinal lengthening from 30% to 100% and significant reduction in calorie intake exclusively by parenteral feeding.

Ethical and clinical discussion on complex patients. There has been a continuation throughout the year of multi-party discussions on ethical questions, for communica- tion training of medical personnel in dealing with ethical dilemmas. Systematic bimonthly meetings have been held involving neonatologists, sur- geons, psychologists, nurses, and parents of children, pre- viously dealt with in the Department of Medical and Sur- gical Neonatology (DNMC). With the help of the expert in bioethics, an open and transparent dialogue was con- ducted on scenarios involving the treatment of patients with the most critical prognoses.

Department of Neurosciences and Neurorehabilitation

In the course of 2014, the Neuromuscular and Neurol- odygerative Diseases Operative Unit and the Laboratory of Molecular Medicine have implemented the systematic use of generic platforms for massive sequencing of the following diagnostic categories: 1) epilepsy; 2) ataxia syndromes; 3) movement disorders; 4) congenital myopathies and muscular dystrophy; 5) spastic paraplegia; 6) leukodystrophy; 7) mitochondrial encephalomyopathies. Furthermore, using targeted sequencing techniques and WES (whole exome sequencing), the unit has been characteris- ting two new genes responsible for mitochondrial diseases and two new phenotypes (phenotype discovery) relating to genes responsible for phenotypes already known.

In 2014, the Neuromuscular Operative Unit developed the project relating to surgery on movement disorders, with preparation of a method, unique in paediatrics, for the treatment of deep cerebral stimulation using robot-aided techniques, and started, through collaboration with the Interventional Radiology unit, the programme involving diagnosis and treatment of paediatric cerebrovascular con- ditions.

The Neurology Operative Unit developed a Project Unit in 2014 dedicated to the ‘Neurosurgery of epilepsy’; this unit has made it possible to coordinate the various components involved in this field, namely neurologists, neurosurgeons, neuroradiologists, psychologists and an- atomical pathologists. The pre-surgical process has been strengthened through the development during the year of the Wada test, which was performed in at least three patients. The year also saw the commencement of an international trial dedicated to children with type II neuronal ceroid lipofuscinosis (NCL), which envisag- es infusion of an enzyme into the cerebral ventricles; the OPBG was preselected along with only two other Euro- pean hospitals.

In 2014, the Infantile Neuropsychiatry Operative Unit began trialling a brain stimulation treatment intended to improve reading ability in children with dyslexia. The pre- liminary results have shown an improvement in reading following treatment over six weeks on a three-weekly basis. Through collaboration with the Fondazione Roma, in June 2014, the Neurorehabilitation Operative Unit launched the operation of the Lokomat rehabilitative system to be used for rehabilitation of walking for children with neurological disabilities. This system can be adapted to the length of the limbs, enabling training from the age of three years. The system has been used by 38 patients, with encouraging results, using cycles of 20 sessions over four weeks. 25 additional children (13 boys and 12 girls, mean age nine years) have completed a period of robotic rehabili- tation, thus a total of more than 500 sessions of training provided by the system.

A further 13 children have been included in a research protocol and undertook an opto-electronic analysis of walking before and after robotic rehabilitation treatment using the Lokomat system, in order to provide objective documentation of the changes occurring. The preliminary results show a clear improvement in walking function. The Clinical Psychology Operative Unit has implemented a series of psychotherapy sessions using the Eye Movement Desensitisation and Processing (EMDR) technique for ad- dicts with post-traumatic stress syndrome.

Department of Nephrology and Urology

In 2014, the Urological Operative Units within the De- partment further developed minimally invasive surgical techniques, which make it possible to perform delicate procedures, reducing post-operative pain and admission periods (laparoscopic and laparoscopic procedures, which have completely replaced traditional open-surgery techniques, organ removal for kidney trans- plants from living donors, bladder autopsynthesis, bladder neck surgery and appendicovesicostomy).

Endourological procedures to treat urinary stones in paed- diatrics have been implemented through the introduction of the micropercuteaneous technique and acquisition of a new laser system. The procedure for endoscopic treatment of obstructive megayearner than high-pressure di- lation has been standardised and is now used regularly in clinical practice. Minimally invasive techniques have also been developed for open surgery, for the treatment of ectopic megayearner and vesicoureteral reflux, resulting in a reduction of more than 50% in hospitalisation period. 20 kidney transplants have been performed, 5 from liv- ing donors, and all with satisfactory recovery of organ function. The total percentage of rejections was 8.7%, all though these were also successfully treated. The Unit also performed three combined liver-kidney transplants.

In the course of 2014, the Unit recorded 289 new diagno- ses of oncohaematological conditions in paediatric-age pa- tients and performed 167 procedures involving transplant of haematopoietic stem cells. These data essentially consol- idate the role of the department as a leading centre in Italy not only in terms of number of transplant procedures per- formed but also number of new diagnoses (approximately 1/7 of those recorded throughout Italy).

The methodological approach designed and applied by the Oncohaematology Operative Unit is innovative, and makes it possible to use a HLA-partially matched related donor (haploidentical), removing the donor’s alfa/beta T cells responsible for the development of graft-versus-host disease and, at the same time, leaving significant quantities of gamma/delta T cells and natural killer cells inside the transplant. These cells are able to protect the child from severe infections, above all in the first four months follow- ing the transplant.

The exceptional results achieved by this approach on pa- tients suffering from non-malignant haematological con- ditions means that the procedure involving HLA-partially matched donors can be extended to all patients who need an autologous transplant of haematopoietic cells for whom it is not possible to identify an HLA-matched donor, either in the family or in the international donor registers, or in which it is not possible to wait for a search to be completed.

The Unit also concluded an international phase II trial based on the use of a bi-specific antibody called Blina- tuzumab in the treatment of acute b-cell lymphoblastic leukaemia (ALL). The results achieved thanks to the use of this antibody as monotherapy in multi-relaps- ing or resistant patients have enabled very rapid progress towards a new protocol, which will be conducted by the Department in 2015, and, subsequently, towards approval of this drug for the treatment of acute b-cell lymphoblas- tic leukaemia. In collaboration with a group operating in the United States, a new immunotherapy/gene therapy protocol has been implemented, envisaging infusion of T cells transduced with the inducible caspase-9 suicide gene, to accelerate post-transplant immune reconstitution. The Unit has also launched a project to produce engrafted T cells that express a chimeric antigen (CAR), which recogn- nises the molecule expressed on the surface of the neuro- blastoma (G2D2), for treatment of neuroblastoma that relapses or is resistant to first-line treatments. This innovative ap- proach can potentially be extended to other tumour types in paediatric-age patients, recognising specific antigens ex- pressed on neoplastic cells.

In 2014, the Immunoinfectology Operative Unit identified five new cases of HIV infection, one of which was in a school-aged child and one in an adolescent, two in young adults (one of whom exhibited an acute infection), and the last in an adult blood donor. Four children with HIV infection were also transferred to our Unit by other regional centres. Follow-up was provided, with reassess- ment of all therapeutic scenarios and appropriate adjust- ment, for 150 African children and adolescents with HIV infection in the village of Sparenza (Tanzania), and follow- up was also provided for 19 newborns exposed to the HIV virus at birth.

The Trials Centre took part in numerous European re- search networks, both public, such as GRIP (Global Re- search in Paediatrics) and ECRIN (European Clinical Research Infrastructures Network), and private, on initi- atives by pharmaceutical companies such as Transcereate and Inspire.

The Endocrinology and Diabetology Operative Unit joined an international network (INKEP) envisaging cul- tural exchanges on specific issues with meetings involving Great Ormond Street Hospital in London, the Necker Hospital in Paris and the Karolinska Institutet in Stock- holm. In research terms, it forms part of the European consortium on the diagnosis and treatment of adenomy- eoneuropathy, with the coordinator being Prof. Patrick Aubourg in Paris and the University-Hospital Paediatric Department being the project leader for the project in- volving treatment of patients suffering from this condi- tion with antipsychotics.

As a centre of excellence, the Unit made a diagnosis of Cushings’ disease in a child exhibiting central prodrome, which subsequently required a bilateral adrenalecto- my. The importance of this diagnosis is linked to the interpretation of the two possible causes of hyperprodu- cution of ACTH in the pituitary gland.
Among the over 550 scientific papers published by OPBG in 2014, we have selected the ones published on journals with the highest Impact Factor. The use of this criterion does not allow to fully express the diversity of our research lines, which cover all paediatric specialisations.

This short review examines the three major scientific disciplines to which the selected publications relate.

**Genetic Diseases**

A new congenital myopathy has been identified, with recessive autosomal inheritance, caused by a mutation of the leptomemin-3 gene; mutations of the APOPT1 gene have been associated with a leukoencephalopathy with cytochrome C oxidase deficiency; mutations in the GTPBP3 gene cause encephalopathy with hypertrophic cardiomyopathy and lactic acidosis; a collaborative study on more than 1,400 patients with 22q11.2 deletion syndrome and DiGeorge/syndactylosial syndrome showed attention-deficit hyperactivity disorder in 10% of cases and psychiatric problems after 26 years in 41% of subjects, demonstrating that this is the genetic condition entailing the greatest risk of psychosis; certain variants of the CADPS2 gene have been associated with autism spectrum disorders; in dystrophin-deficient myopathies, nine proteins have been identified that are correlated with the progression and severity of the condition; it has been demonstrated that translation through use of a ribosome entry site in exon 5 inducible with glucocorticoids attenuates the phenotype of the dystrophin-deficient myopathy and offers a potential treatment approach in a subset of patients; it has been demonstrated that cerebral MRI combined with molecular studies make it possible to sub-classify hypomyelinating leukodystrophies; the analysis of a large group of myopathic patients with lamin A/C mutations has demarcated the natural progression of the illness and its frequent cardiac involvement; it has been observed that cystine crystals activate inflammasomes and identify a new mechanism underlying nephropathy in the setting of the illness, and it has been demonstrated that cystine crystals activate inflammasomes and identify a new mechanism underlying nephropathy in the setting of the illness.

**Complex Diseases**

It has been demonstrated that the E167K polymorphism in the TM6SF2 gene increases susceptibility to progressive non-alcoholic steatohepatitis and protects against cardiovascular risk; the gene coding for the plasminogen receptor that activates urokinase is a marker for controlling inflammation of the mucosa in chronic inflammatory diseases of the intestine; patients with rare variants in the NLRP3 gene are at risk of developing a form of cryopyrin associated periodic syndrome (CAPS), with neurological involvement and deafness before the age of six months; there has been a review of the clinical characteristics, treatment and natural development of macrophage activation syndrome associated with idiopathic juvenile rheumatoid arthritis; it has been demonstrated that an inhibitor of the interleukin-6 receptor provides long-term control of the symptoms of the disease; it has been observed that a sub-population of CD4+ T lymphocytes in the circulation and in the synovial fluid in patients with idiopathic juvenile rheumatoid arthritis has the diagnostic value and correlates with the activity of the disease; there has been a review of the natural development in a group of patients with TNF-receptor-associated autoinflammatory syndrome.

**Oncohaemato logical Diseases**

It has been demonstrated that the mesenchymal stem cells are able to incorporate and release active drugs through their membrane microvesicles; an original protocol has been developed based on the removal of α4β7 T abd B cells from the bone marrow of HLA-haploidentical donors, making them safe and effective in the treatment of malignant tumours in infants; the prophylaxis of bone marrow rejection disease, using Sirilumus, promotes the in vivo expansion of Treg cells and makes it possible to use haploidentical donors; bone marrow donors with the KIR B haplotype have lower recidivism rates following haploidentical transplant in acute lymphoblastic leukaemia; in patients with acute lymphoblastic leukaemia, it has been demonstrated that those with limited response to cortisone have a favourable outcome, while those with minimal residual disease (MRD) have a poor prognosis, following stem cell transplant or intensive treatment; in a sub-group of patients with germline mutations in the RRAS gene, a rare phenotype of Noonan syndrome has been identified, while the mutations activating that gene have been associated with leukoaemogenesis with various phenotypes; it has been demonstrated that juvenile acute lymphoblastic leukaemia with 6;11 translocation (AF6) involves a oncogene that activates RAS and is a potential therapeutic target; CD1c autoreactive T cells recognise a new class of autolipids that accumulate in leukaemia cells, providing the conceptual basis for the development of immune-surveillance and perhaps immunotherapy; a new form of hereditary thrombocytopenia has been identified, with a low risk of bleeding correlated with mutations in the alpha-actinin-1 gene.

**Scientific output**

OPBG’s scientific output in 2014 confirms its continuous growth, having published over 550 articles (559) with a standardised Ministerial Impact Factor (IF) value that, for the first time, has exceeded 2,000 points (2,119).

The mean IF per researcher has reached 10.15 and the mean cost for each IF point has been €2,626. Funding obtained has increased significantly through the national and international grant applications, with an overall success rate of 42%.

Figure 6 shows the trend in gross IF values, standardised IF values and IF values standardised according to Ministerial criteria, over the period 2003-2014.
Research funding

National and international research grant applications, by OPBG’s researchers, involving innovative, high-profile projects, has determined in 2014 the increase by 18% of total funds for scientific research.

The organisations that have contributed most to OPBG’s research in 2014 are public bodies (Ministry of Health; European Commission; contribution from the ‘5 per thousand’ scheme; Ministry of Education, University and Research (MIUR); Lazio Region; Italian Medicines Agency (AIFA); National Institutes of Health (NIH), and Research foundations and associations, charitable associations and private entities (Associazione Italiana per la Lotta al Neuroblastoma; Associazione Italiana per la Ricerca contro il Cancro (AIRC); Associazione Italiana Studio Malformazioni (ASM Onlus); Associazione La Vita è un Dono; Associazione Nicolò Valenti; Associazione Italiana Sindrome di Williams; Cystinosis Research Foundation; CONAD; Fondazione Bulgari; Fondazione Celiachia; Fondazione Just Italia; Fondazione Chiarlemagne; Fondazione Chiesi; Fondazione Nicolò Cusano; Officium; Telethon).

Clinical trials

In 2014, 360 clinical studies, approved by the local ethical committee, have been performed, enrolling a total of 11,796 patients.
The Research Area is committed to improving the understanding of simple hereditary diseases, by identifying new clinical conditions and their biological mechanisms, and by developing new diagnostic tests and guidelines, using a translational approach focused on potential immediate usability by patients. A significant portion of these activities are focused on rare, ultra-rare and orphan diseases. The focus on genetic diseases is justified by their considerable impact on patients admitted to Paediatric units. Following is the description of the activities of the Research Units belonging to the Research Area.

Clinical Genetics and Dysmorphology  
Chair: Maria Cristina D’Aglio  
Aims: identification of the molecular basis of genetic syndromes; genotype-phenotype correlations; drafting of clinical guidelines.

Main results in 2014  
- Identification of a new gene associated with Noonan syndrome (RRAS gene) and extension of the diagnostic platform for patients with clinical profiles related to RA-Spondylopathies, using next-generation sequencing techniques;  
- characterisation of a new phenotype of type 1 nevoid-bromatosis correlated with a specific mutation of the NPI1 gene;  
- identification of a sub-group of patients with Hennekam syndrome caused by a mutation of the FATS gene, allelic to van Vlodregen syndrome.

Endocrine Diseases  
Chair: Marco Cappa  
Aims: study of the causes of specific endocrine conditions, such as precocious puberty and height deficit; analysis of genotype-phenotype correlations in specific endocrine conditions, such as congenital adrenal hyperplasia and non-autoimmune primitive hypoadrenalism; assessment of the co-morbidities related to obesity, mainly bone morphology.

Main results in 2014  
- Definition of the value of Magnetic Resonance Imaging focused on the hypothalamus-pituitary gland in central precocious puberty;  
- determination of metabolic syndrome and type 2 diabetes as co-morbidities of oncology patients;  
- validation of the use of the GLP-1 receptor agonist in Prader Willi syndrome.

Metabolic Diseases  
Chair: Carla Dusi-Viti  
Aims: translational research in the field of metabolic diseases, with particular reference to the transfer of metabolomic analysis to clinical activity; testing of new therapies; use of evidence-based medicine as a model for the development of guidelines.

Main results in 2014  
- Development of laboratory methods through tandem mass spectrometry: a) assay for plasmatic oxysterols, a new biomarker for Niemann Pick type C disease; b) haemato spot assay of carnitine esters for diagnosis of atypical forms of methylmalonic acidemia;  
- drafting of international guidelines for proionic and methylmalonic acidemia and description of the natural development of CHC deficiency;  
- validation of the protocol for differential diagnosis of hyperinsulism.

Neuromuscular Diseases  
Chair: Enrico Silvio Bertini  
Aims: development of translational medicine in the field of neuromuscular and neurodegenerative diseases; development of algorithms for myopathy, enzymatic and genetic diagnosis; definition of the natural development of rare diseases for the development of RCT clinical trials.

Main results in 2014  
- Drafting of international guidelines for the diagnosis of congenital myopathy;  
- characterisation of new phenotypes in leukodystrophy;  
- characterisation of two new disease genes associated with mitochondrial encephalopathy and the gene of a nemaline myopathy.

Neurological Diseases  
Chair: Federico Vigezzi  
Aims: development of studies dedicated to specific pathologies requiring high-level expertise, with particular reference to resistant epilepsy; neurosurgical treatment of epilepsy, headache, movement disorders, and demyelinating conditions; follow-up of neonates with hypoxic-ischaemic encephalopathy; new surgical perspectives for patients suffering from pharmacoresistant dystonia who are not candidates for movement disorder surgery.

Main results in 2014  
- Definition of the protocol for treatment of resistant epilepsy using the ketogenic diet;  
- definition and preparation of the genetic panel for movement disorders;  
- new surgical treatment methods for patients suffering from severe pharmacoresistant dystonia.

Kidney Diseases  
Chair: Francesco Emma  
Aims: study of the physiopathological mechanisms of nephro-philic cytostasis and immune-mediated kidney diseases; clinical research in the field of nephrology; participation in various registers of kidney diseases.

Main results in 2014  
- Definition of specific programmes for activated transcription in nephro-philic cytostasis;  
- characterisation of the reconstruction of the B lymphocyte population in patients with nephritic syndrome treated with anti-CD20 monoclonal antibodies;  
- definition of cardiac function in infants suffering from chronic kidney failure using speckle-tracking echocardiography and definition of new algorithms for assessment of cardiac mass.

Metagenomics  
Chair: Lorenza Putignani  
Aims: development of the Italian interface for the Orphanet project, the most important international database dedicated to rare diseases.

Main results in 2014  
- Implementation of the Orphanet database with new data;  
- active participation in the definition of the first National Plan for Rare Diseases in Italy, adopted in October 2014;  
- definition of a more effective communication system through management and daily updating of the Orphanet-Italia Facebook page, the creation of YouTube output, the distribution of the Orphanet App for Android, Iphone and Ipad, and the creation of a video for 2014 World Rare Disease Day.
The Research Area studies and identifies risk factors for common diseases, taking into account genetic, exogenous and environmental causes. Research relates mainly to infections and to hepatic diseases, to obesity, to neuropsychological and to cardiological diseases, as well as to vaccinations and allergies, with the common intent to develop strategies for data analysis, including on a cellular, clinical and social level, able to allow an integrated approach and promote the identification of complex patterns among the phenotypes expressed. Following is the description of the activities of the Research Units belonging to the Research area.

**Predictive Medicine**
Chair: Alberto Eugenio Tozzi

Aims: development of techniques for remote monitoring of chronic patients; syndromic surveillance through analysis of natural language by internet; promotion of infant health even before conception; analysis of the impact of vaccinations.

**Main results in 2014**
- Implementation of a prototype for remote monitoring of chronic patients using smartTV;
- analysis of the prevalence of paternal risk factors for adverse pregnancy outcomes;
- demonstration of the existence of a synergy between the changes in insulin and in iron metabolism in causing the dysmetabolic conditions often associated with obesity.

**Hepatic Pathologies**
Chair: Valerio Nobili

Aims: study of Non-Alcoholic Fatty Liver Disease (NAFLD) in children using an integrated approach involving biological and clinical aspects, aiming at identifying mechanisms and risk factors that could potentially be useful for diagnosis, prevention and treatment.

**Main results in 2014**
- Verification of the effectiveness of non-pharmacological treatments on hepato-metabolic parameters in obese subjects suffering from Non-Alcoholic Fatty Liver Disease (NAFLD) and assessment of the benefits of the first study using intragastric balloons in obese subjects;
- characterisation of the role of inflammation in the tissue/intestine/liver axis in paediatric Non-Alcoholic Fatty Liver Disease (NAFLD);
- validation of new algorithms and predictive genetic and non-genetic tests in assessing therapeutic success and drafting of guidelines for the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) for liver biopsy.

**Neuropsychiatry**
Chair: Stefano Vicari

Aims: definition of the neuropsychological and psychiatric profiles of children with developmental problems and of the evidence-based treatment procedures for children with developmental problems.

**Main results in 2014**
- Demonstration of the effectiveness of cerebral stimulation in treating developmental dyslexia;
- definition of the altered cognitive processes in autism spectrum disorders, in intellectual disability and in learning disability;
- definition of the effects of genotype on the neurocognitive phenotype in patients with genetic syndromes.

**Cardiopathies**
Chair: Giacomo Giovannetti

Aims: diagnosis and treatment of congenital cardiovascular malformations, acquired heart diseases and heart rhythm abnormalities; clinical and diagnostic support for surgery in terms of pre-operative and post-operative management of patients with congenital heart problems.

**Main results in 2014**
- Development of a protocol for anticoagulation and antithrombosis in patients with non-implanted mechanical cardiac support;
- development of protocols for acute neonatal dialysis;
- measurement of reference haemodynamic values in infants after heart surgery using specific monitors.

**Immunology and Drug Therapy**
Research Area
Chair: Paolo Rossi

Aims: study the pathogenetic mechanisms of rheumatological diseases in children to identify new biomarkers and therapeutic targets.

**Main results in 2014**
- Demonstration of the role of the reduced expression of the TiKα receptor for Nerve Growth Factor (NGF) in chronic inflammation;
- demonstration of the role of γ interferon in haemophagocytic lymphohistiocytosis associated with rheumatic disease with identification of IFN γ as a therapeutic target in autoimmune system diseases;
- demonstration of the role of inflammasome and tissue inflammation in nephrotic cystinosis.

**Drug Therapy**
Chair: Carlo Giaquinto

Aims: definition and identification of the correct use of drugs in children. In particular, the European Neomero Project addresses the efficacy of Meropenem with standard therapy in treatment of delayed sepsis in newborns and children aged less than 90 days. The European GRIP Project increases the understanding among Healthcare Operators about the use of drugs in children, harmonising and validating the appropriate use of biomarkers.

**Main results in 2014**
- As part of the Neomero Project: enrolment of 20% of the European patients included in the study; commencement of the follow-up nutritional study at 24 months after enrollment; commencement of the analysis of the results of Immunogenetics study.
- As part of the GRIP Project: organisation of the first international biennial Conference on Paediatric Medicine Development and Evaluation; optimisation of the protocol for systematic review of biomarkers for neonatal sepsis.
The Area has the main objective of optimising diagnostic and therapeutic approaches in paediatric patients suffering from malignant haemopathies and solid tumours, using innovative drugs and cell therapies, by means of biological and clinical research approaches with a strong translational character. Studies on adult stem cells and on immune and gene therapy are oriented towards the development of innovative therapeutic techniques. Following is the description of the activities of the Research Units belonging to the Research area.

**Tumour Immunotherapy**

Chair: Franco Locatelli

Aims: implementation of gene therapy programmes for neuroblastoma and lymphoproliferative disorders; study of innovative antitumour adoptive immunotherapy approaches; study of the mechanisms regulating antitumour activity of NK cells and of γδ T lymphocytes.

**Main results in 2014**
- Definition of γδ T lymphocytes antitumour activity and of the influence of exposure to oleanolic acid on lymphitic activity;
- Identification of a sub-population of NK cells with the ability to secrete interferon-γ and with a specific lytic activity on the blastic cells of ALL;
- Identification of a protective effect on leukaemia impact on the part of donors with the B KIR haplotype of NK cells, in the context of ALL in children;
- Identification of a different expression on lymphoid leukaemia cells in children and adults of NK cell activation receptors, which make children more susceptible to the lethal effect of innate immune effector cells;
- Identification of lipid self antigens with immunogenic potential that accumulate selectively in leukaemia cells and can be attacked by T lymphocytes with selective specificity for these molecules.

**Regenerative Medicine**

Chair: Maurizio Muraca

Aims: study of the role of adult stem cells in regenerative medicine approaches applied to paediatric pathologies; development of protocols to transfer the use of adult stem cells to clinical practice; development of murine experimental models for the analysis of degenerative diseases.

**Main results in 2014**
- Demonstration of the effect of microvesicles derived from mesenchymal stromal cells on the growth of glioblastoma multiforme cells and on the function of T lymphocytes;
- Demonstration that specific cytostatic drugs can be incorporated into mesenchymal stromal cells and released into extracellular space, in order to inhibit tumour growth;
- Identification of the role played by chondroaderin on osteoclastic function and on bone resorption processes.

**Cell Therapy**

Chair: Franco Locatelli

Aims: study of the haematopoietic stem cells in vitro study of the immunoregulatory characteristics of mesenchymal stem cells and their action on the cells involved in an inflammatory response; in vitro and in vivo characterisation of the effectiveness of the mesenchymal stem cells obtained from healthy donors; study of the immunoregulatory activity of mesenchymal stem cell microvesicles to assess their effect on B and T lymphocytes.

**Main results in 2014**
- Validation of the clinical results obtained by combining bone marrow transplants with transplants of cells obtained from cord blood of an HLA-compatible family donor in patients suffering from malignant and non-malignant haematological disorders;
- Validation of the kinetics of haematopoietic engraftment after transplant of cord cells and definition of the impact of failure of engraftment on final patient outcomes;
- Characterisation of the role played by the immunogenic structure (HLA typing) of a patient on the probability of identifying a non consanguineous compatible donor that may be used for transplant purposes;
- Demonstration that transplanting haematopoietic stem cells from HLA-identical family donors, thanks to the innovative manipulation approaches based on the physical elimination of the lymphocytes that express the α and β chains of T cell receptors, can cure approximately 90% of patients suffering from a non-neoplastic disease;
- Definition of the role played by mesenchymal stromal cells in the number and function of B lymphocytes in the presence or absence of T lymphocytes.

**Clinical and Technological Innovations**

**Research Area**

Chair: Pietro Berriello

The Research Area aims at developing and trialling the most promising technological innovations and improvements in corporate safety. This objective is achieved by analysing the state of the art in technology, by constantly focusing on innovative ‘medical technologies’ and by developing knowledge and techniques providing the hospital with the most advanced know-how. Following is the description of the activities of the Research Units belonging to the Research area.

**Health Technology Assessment and Safety**

Chair: Matteo Rittovano

Aims: validation and validation of the most innovative technologies with the greatest potential benefits, including guiding the Hospital’s technological investments; development of new expertises, intended for the identification of appropriate measures for prevention of the primary work-related risk factors (biological, chemical, physical and psychological) and the corresponding biological mechanisms.

**Main results in 2014**
- First global Hospital-Based HTA report on robotic surgery in paediatrics;
- Demonstration of the persistence of immune memory to HBV in non-responder vaccinated individuals;
- Description of the biological effects on neural stem cells of exposure to electromagnetic fields generated by NMR.

**Neurorehabilitation and Robotics**

Chair: Enrico Castelli

Aims: integrated management of the complex issues related to rehabilitation in children with the outcomes of a neurological lesion, by means of indicators of motor performance, using opto-electronic analysis systems, analysis of the functional recovery processes associated with variations of neuronal plasticity, design of innovative rehabilitation strategies, application and design of innovative technologies and robotics.

**Main results in 2014**
- Analysis of the follow-up process of patients with kidney transplants and acquisition of treatment protocols according to national and international best practice, by Business Process Management (BPM) tools;
- Implementation of the kidney transplant follow-up management process on an Intranet platform, the automatic creation of the treatment process on the basis of the specific protocols and the management of events requiring interruption of such protocol;
- Automatic definition of the clinical schedules for patient management and automatic acquisition, within the BPM logic, of patient’s clinical data from the various sources within the hospital, in a single “patient-centred” applicative context.

**Operational Innovations**

Chair: Nicola Rovisco

Aims: support the identification of operational and clinical innovation models; develop applicative tools able to obtain a consistent improvement in efficiency and effectiveness by coordinating technological, medical and administrative expertises.

**Main results in 2014**
- Installation and start-up of a robotic system for rehabilitation of walk in children with motor disabilities due to neurological damage;
- Definition of reliable, repeatable and sensitive measures to record all changes, in neurodegenerative conditions;
- Support of psychological support for families, intended to promote high-quality parent-child relationships.
Clinical Care and Management Innovation Research Area
Chair: Massimiliano Raponi

The Research Area is committed to evaluate and measure the clinical and organisational impact of actions aimed at improving the quality of care, understood as clinical and organisational appropriateness and satisfaction of patients and operators. The Area also develops innovative tools for the evaluation of the performance and efficiency of care and administrative processes within the healthcare environment, including analysis of costs, effectiveness and expected benefits, definition of care needs and development of innovative organisational and management models that promote the spread of good clinical practice and improve efficiency. Following is the description of the activities of the Research Units belonging to the Research Area.

Medical and Surgical Outcomes and Pathways
Chair: Marta Luisa Ciofi degli Atti

Aims: analysis of the safety, effectiveness and efficiency of care interventions; evaluation of treatment outcomes; identification of quality indicators based on routine medical databases and performance of intervention studies to promote evidence-based medicine

Main results in 2014

• Documentation, in a multicentre study, that intra-hospital diffusion of guidelines on perioperative prophylaxis is improving appropriateness, compliance and timing of antibiotic treatment;
• evidence, through analysis of long-term outcomes in patients with short bowel syndrome undergoing parenteral feeding, of the need for a multidisciplinary approach to guarantee appropriate growth;
• demonstration of satisfactory remote electromechanical functionality of pacemakers in the first year of life.

Nursing Sciences
Chair: Emanuela Tiozzo

Aims: the promotion of research activities focused on improving the quality of nursing and technical care provided to paediatric patients.

Main results in 2014

• Trialling of the Early Warning Bedside PEWS systems in the clinical documentation;
• validation of the Empathic-NIC questionnaire, to explore the satisfaction and experience of parents of newborns discharged from Neonatal Intensive Care Units;
• trialling of an app for evaluation of pain at home for children operated on in Day Surgery, with real-time registration and display on an electronic platform.
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