

PRELIMINARY PROGRAM

8,00 - 9,00 **Registration of participants**
[E' preferibile registrarsi on-line a questo link](#)
 (please register on-line)

9,00 - 10,00 **Welcome address to the Authorities**

- **Alga Rossi**, President Milan Section FIDAPA BPW-Italy
- **Leda Mantovani**, President North-West District FIDAPA BPW-Italy
- **Pia Petrucci**, National President FIDAPA BPW-Italy
- **Giuseppina Bombaci**, European Coordination Secretary BPW International
- **Luisa Monini**, International Health Committee Chairperson BPW-I
- **Yasmin Darwich**, President BPW International

10.10 – 10.30 **Tribute to Rita Levi Montalcini**

Introduced by **Bettina Giordani**

- **Pia Petrucci**, President FIDAPA- BPW Italy
Tribute to Rita Levi Montalcini: When Science turns into Art and Art into Science
- **Pina Tripodi**, Collaborator of prof. Rita Levi-Montalcini over 40 years
Education key of development: strategy for the freedom to live

Panel 1

10,35-11,45 **The thousand faces of gender violence**

introduced by **Annalisa Voltolini**

- **Alessandra Kustermann**: "Helping women victims of gender violence: a major social and health challenge"
- **Dora Mauro**: "Staying alive: femicides."
- **Donatella Albini**: "The obstetric violence"
- **Alga Rossi**: "Invisible children, violence assisted"

Panel 2

11,45-13,10 **Socio-health policies in a gender prospective**

Introduced by **Luisa Monini**

- **Eufemia Ippolito**: "The European policies on women's health"
- **Enrichetta Bellini**: "Immigration and women's mental health"
- **Cristina Gorajski Visconti**: "Focus on women in rural areas"
- **Yasmin Darwich**: "Beijing + 20: equality as a target within 2030"

13,10-14,30 **Lunch break**

Panel 3

14.30 – 15.30 Gender medicine, a teamwork

Introduced by **Maria Antonietta Banchero**:

- **Fulvia Pedani** “The reality of genetics: reality or fantasy?”
- **Olusola Ladokun** “*Hunteria umbellata*: a phytomedicine efficient against diabetes”
- **Gianna Ferretti** “ The link between maternal obesity and childhood”
- **Mercedes Perez** “The burden of health only for being a woman”

15,30- 16,00 Coffee break

Panel 4

16,00- 17,30 Global Women Health

Introduced by **Luisa Monini**

- **Andrea Poli**: “From Mediterranean diet to nutraceuticals”
- **Rosa Maria La Scola** :“Food between health, knowledge and flavours”
- **Gisele Nissack** : “The Red Belt “
- **Anna Parrini** : “Nutrition and cardio-metabolic prevention from intrauterin life to menopause”
- **Giulia Galantino, Lucia Di Molfetta**:“The origin of primary foods for a proper nutrition”
- **Luisa Monini**:“Tommy & Ollie for Health”

17,20- 17,30 Discussion

17,30, 18,00 Antoinette Ruegg: From the Commissions to the Pilot and Taskforces projects

Patient Voice—Join us in making the voice of rare diseases heard

It is referred as rare disease the one affecting not more than five people out of 10,000. The World Health Organization has classified as rare approximately 6,000 diseases, whose 80% are caused by a genetic anomaly. The definition of rarity for each single disease clashes with the huge number of people affected, at least 30 million in Europe and about 2 million in Italy; approximately 20,000 new cases are recorded every year and 70% of them are children. A tragedy. We wonder why, with such a high number of people affected by these diseases, **we keep using the word "rare"**. The rare patients and their families have more or less the same fate; getting to the diagnosis after a tortuous and long journey (about 7 years to get a diagnosis). These diagnoses do not often lead to any chance of a cure and therefore of any healing.

For this and other reasons, also financial ones (the average annual cost for a family is 7,000 Euros) **the "invisible" patients have teamed up and today, speaking on behalf of 278 associations representing them,** say loud and clear that they are tired of being seen as numbers and ask the Health Authorities in charge for an updated official list of the rare diseases (still unchanged since 2001 with 600 diseases recognized as such). The updating of the list is of fundamental importance as it allows patients to gain visibility and therefore to benefit from all the health services required. The Associations are urging the State to support research and, as per European directive, to grant fiscal subsidies to the pharmaceutical companies which decide to make drugs to cure the numerous diseases still waiting for the drug that can save lives. Besides, over the last few years the study of rare diseases has turned out to be useful also to improve the knowledge and the treatment of much more common pathologies, from the stroke to the heart attack. With this in mind, investing in research can be an advantage for the pharmaceutical company as well. In Brescia, at the Azienda Spedali Civili, the Rare Diseases Service works hard and provides a clinical and administrative support to the management of patients suffering from rare diseases who belong to the hospital. The clinical activity includes: an information service for the users who need to get details about rare diseases (contact people, exemption from the fee for medical visit, associations to contact....etc); activity of genetic consultation (in collaboration with several medical teams working in Operating Units of Children's Hospitals and of the Spedali Civili); service of coordination of psychological undertaking. The Administrative Tasks of the Service are: training for the specialists who are the contact for the R.D.s and coordination of the activities they carry out which has to be compliant with what is set by the national and regional regulations, test of achievement of the targets set by the Lombardy Region and by the Coordination Centre for Rare Diseases Aldo and Cele Daccò, the promotion of initiatives to train local physicians, the promotion of contacts with patients' associations, the check of the costs of pharmaceutical supplies to rare disease patients (in collaboration with the Internal Chemist's)). In July 2009

the NHS unit in Brescia set up a centre dedicated to rare diseases and decided to study and monitor these cases too in order to assess their size both in terms of numbers and of socio-health demand. Additionally, the close collaboration between the Centre in Brescia and the Centre of Regional Coordination "M: Negri" in Ranica ensures the highest expertise and the best information about the various diseases, monitoring widely the whole territory.

Rare disorders without borders, this is the slogan of the sixth international day of the Rare Diseases which will be celebrated worldwide on February 28 to show that the fight against these diseases requires a cooperation without borders. The main theme this year then is the promotion of a cooperation that goes beyond any cultural, social, scientific, economic, bureaucratic or political restriction.

With reference to the last three, it is worth mentioning the important contribution the representatives of Cittadinanzattiva (Active Citizenship) are giving so that the updating of the official list of rare diseases (still unchanged since 2001 with 600 diseases recognized as such) would not be bound to the approval of the new ELAs (essential levels of assistance), according to which the "Balduzzi proposal" is still at the Ministry of Finance, but rather it would be included in the National Plan for Rare Diseases 2013-2016. Also because the new ELAs and the Minister Balduzzi, in late December, **introduced one-hundred-and-ten new rare diseases!** A note from Cittadinanzattiva reads that in the Plan there should also be "the forecast for additional financial resources for rare diseases; the finalising within sixty days of a public offer for neonatal screenings extended to more rare diseases (it is currently guaranteed nationally only for three pathologies), the commitment to ensuring services of psychological support to those affected by a rare diseases and their families; the commitment from AIFA (drug Italian agency) to speeding up the approval of drugs already recognized in Europe for the cure of rare diseases and from the Regions to making them available to people straightaway; finally, the commitment to ensuring programmes of civic audit of reference centres and, more generally, of the national network of rare diseases".

The updating of the list is of fundamental importance as it allows patients to gain visibility and therefore to benefit from all the health services required. The 278 Associations of Rare Diseases Patients are urging the State to support research and, as per the European directive, to grant fiscal subsidies to the pharmaceutical companies which decide to invest in the study of life-saving molecules for the numerous "rare patients" still without a chance to be cured.

A case apart is that of the Dompè Group which decided to focus research and pipeline on rare diseases and precisely on the cure of some diseases of the eye like the neurotrophic keratitis which affects 1 individual out of 10,000. Dompè, by taking over Anabasis Srl an Italian Biotech company specialized in the research in the field of eye pathologies, managed to develop a stable process suitable for the mass production of the recombinant human NGF. So, for the first time over 50 years after the detection of the Nerve Growth Factor, which made Rita Levi Montalcini win a Nobel prize, a company was able to promote

the discovery and to get close to marketing the product. The researchers of Anabasis Srl indeed have already got very important results from the clinical point of view, showing that the NGF has a therapeutical potential for the diseases affecting both the front part of the eye (neurotrophic keratitis, dry eye syndrome) and the rear part (retinitis pigmentosa, glaucoma). We would have to wait until 2015 to get the eye drops. Dompè's turning point, with the purchase of the global rights to develop and market the NGF, puts the company in pole position in a strongly expanding field that is linked to the ageing of the world population and shows how a sharp far-sightedness can affect choices which eventually turn out to be "win-win" for everyone, those who invest and those who have a benefit in terms of health and quality of life.

We hope that the pharmaceutical company from Lombardy could set an example for other companies to make sure that less rare diseases are left without cures because these diseases are rare but numerous.

Their prevalence is of 5 cases out of 10,000 inhabitants, the different typologies are over 7,000. There are at least 30 million people affected by rare diseases in Europe; approximately 2 million are the "rare patients" in Italy where about 20,000 new cases are recorded every year of which 70% are children. A tragedy!

In Brescia and its province there are 5135 people suffering from rare diseases recognized by their own exemption code, to which 3587 celiac patients are added (a disease still considered rare from a regulatory point of view, but not anymore from an epidemiological point of view, given the huge rise of cases). In order to provide concrete support to the patients and their families the local Health Authority introduces the "donation for the rare diseases", after an experimental journey started in 2009. It is a financial support awarded to the family to integrate the health services with further forms of assistance which the patient should otherwise pay for as they are not supplied by the National Health Service. The main idea is to seal with the family an "agreement of cure" with a mutual commitment from the local Health authority and the caregivers.

"The donation for the rare diseases is a unique project in Lombardy which can work as a model for other territories and is set up following significant steps already taken by the local Health Authority in Brescia with the establishment of the Centre for Rare Diseases in 2009", underlines Carmelo Scarcella, General Manager of the local Health Authority in Brescia.

Research brings hope to people living with a rare disease."