

newsletter

THE PATIENT AT THE CENTRE INNOVATION AND NEW CHALLENGES IN 2017

INSIGHTS FROM THE FOUNDATION

"E-HEALTH BETWEEN HOAXES AND THE TRUTH: THE TWO SIDES OF ONLINE HEALTH"

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The patient at the centre - innovationand new challenges for 2017

Our Foundation had an early start to the year's activities with the workshop titled "E-Health between hoaxes and the truth: the two sides of online health". Held last January 26 in Rome, this event drew considerable interest and also media attention.

Our Foundation, whose purposes are to promote, support and contribute to science progress, has been working on the theme of online health information since 2015. It started with the workshop

titled e-Health: progress or danger? and continued though last fall's innovative course on Health Literacy directed at representatives from Patient Organisations, and the January 2017 workshop.

This most recent event provided an opportunity for exchange and debate involving representatives from Patient Organisations, institutions and experts in the field. It also featured the presentation of the first **Guide to Health Literacy**, an easy-to-use and helpful reference not just for patients but more



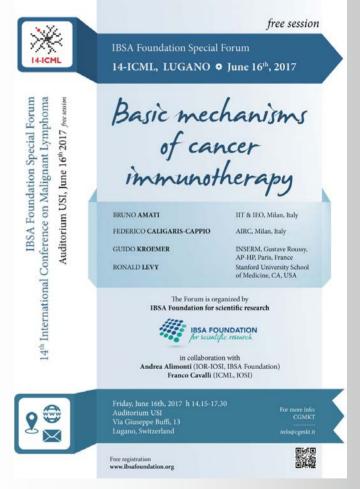


Insights from the foundation

generally for people who search health information online. That Guide also contains some useful advice on how to get the most out of conversations with healthcare providers.

This issue of our newsletter also showcases a notable initiative our Foundation has been supporting for the last few years and will continue to support in light of the positive results it has been yielding. It is the Movie Program for children and teenagers hospitalised at the Lugano Civic Hospital, an initiative started in 2014 that we are particularly proud of sustaining. Run by an educator under the supervision of the Chief of the Paediatric Department Valdo Pezzoli, the movie program offers the young patients, who are enthusiastic about it and look forward to this appointment, moments of recreation and emotional release and, at the same time, opportunities for reflection and exchange.

Our Foundation continues with its commitments and is ready to get going on the next Forum titled "Basic mechanisms of cancer immunotherapy" scheduled to be held next June 16 in Lugano. This next Forum will bring together scientists and experts from all over the world for discussions on what is considered to be one of the biggest breakthroughs of recent years.







WORKSHOP

"E-Health between hoaxes and the truth: the two sides of online health"

The Internet's enormous ability to readily provide information can become dangerous if users are not capable of evaluating the reliability of what they find. The more sensitive the subject matter, the truer this is. To analyse the issue, on 26 January 2017 the IBSA Foundation held a conference entitled "E-Health between hoaxes and the truth: the two sides of online health". The highlights of this meeting of experts, scholars, representatives from patient organisations and Italy's National Health Institute included the presentations of the first Guide to Health Literacy and of the results of a survey which our Foundation conducted for the occasion.

Over 88% of Italians (93.3% among women) turn to the Internet when they need information on health topics and 44% believe that seeking this type of information online is only slightly or not at all risky. The combination of the data regarding the frequency with which people look up for health-related information online and the degree of trust people have in the Internet, reveals that individuals aged between 24 and 34 make enormous use of the Internet as "support" in their searches, but are more sceptical than people in the 45-54 age bracket, while those over 65 years of age are sceptical a priori (they use the Internet rarely and see it as a "highly risky" source). The most alarming figure is that regarding online hoaxes, particularly on social







networks: almost half of those interviewed don't seem to be worried about that.

Use of the Internet for health-related searches varies greatly according to the level of education of users: 96% of college graduates turn to the Internet for this type of information versus only 24.5% of people who stopped studying after elementary school.

Additionally, little attention is paid to sources: 44% trust the top results on the page with a significant difference between 18 to 24 year-olds (55% of those surveyed) and those over 65 years of age (barely 22.7%). And yet greater awareness of the risks related to Internet use and increased basic knowledge of health in general could help empower Internet users, beginning with careful examination of sources. According to Antonio Gaudioso, Secretary General of Cittadinanzattiva "it is primarily when individuals are searching the Internet for information related to health - and the survey demonstrated that this is happening with increasing frequency - that basic knowledge becomes the only 'weapon' to defend against partial or false information. However, when we talk about Health Literacy, this is not the only thing we are referring to: in fact, increased knowledge also means a better doctor-patient relationship." A theme still not much discussed in Italy and yet of increasing relevance, health literacy triggers a virtuous circle that often results in more effective treatment and, therefore, better health.

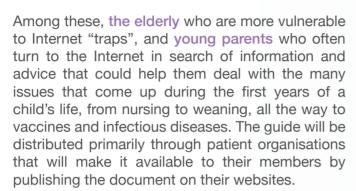
The first guide created to help people defend themselves against Internet hoaxes

Drafted for the workshop and presented during the

event, the first Guide to *Health Literacy* includes a series of practical and easy-to-understand tips and advice for learning how to defend oneself against incomplete or false information circulating on the Internet, as well as for improving doctor-patient communication. The first fundamental rule of the guide is "Check the source". It is, in fact, necessary to check the credentials of the source of the information and preferably turn to the official websites of well-known reliable organisations. The guide was created for everyone's use, not just patients but people in general, and can be particularly useful to certain population groups.







Health Literacy: the opinion of patient organisations

After the *Health Literacy* course organised by the IBSA Foundation which took place in Rome and Milan this past autumn with the contribution of Peter Schulz - professor of Communication Theories and Health Communication, Director of the Institute of Communication and Health at the University of Southern Switzerland, Lugano - and Michaëla Liuccio - Chair of the Biomedical Scientific Program, Sapienza University, Rome, Italy - a series of questions were asked of a representative sample of Italian patient organisations. The results of the survey show that only half of interviewees admit to referring rarely to the term *Health Literacy*. despite recognising its importance. When asked what measures should be put in place in order to avoid potential harm to patients with a low level of Health Literacy, the most common suggestion given by respondents when answering this important question was to strengthen information, scientifically based if possible, as

well as to educate doctors and patients. The majority of those surveyed believe that in order to increase the probability that health professionals communicate with patients according to their level of *Health Literacy*, it is above all necessary to make communication skills an integral part of medical training for doctors and nurses. Finally, in response to the question of what can be done to improve patients' *Health Literacy*, almost all of the polled organisations suggested creating a website for patients that provides useful medical information and gives them an opportunity to ask questions anonymously, as well as urging patients to prepare for a doctor's visit by, for example, making a list of potential questions to ask.







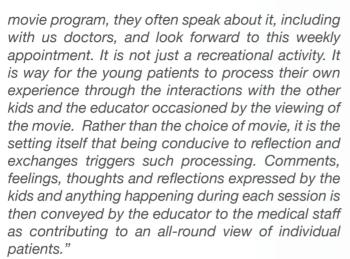
The Lugano Regional Hospital is a leading medical centre including in paediatric treatment and care. Our Foundation provides support for young patients at this hospital, who at times need long-term inpatient care and treatment. We have been doing so including by funding since 2014 a movie program for kids at this hospital. Once a week young patients aged 11 through 16 years meet up

to watch a movie together, and discuss it at the end, under the guidance of a highly-trained educator.

"Since 2014 over 50 children and teens have been engaged in this program that is part of our multidisciplinary approach to treatment and care" – explains Dr. Valdo Pezzoli, Chief of the Paediatric Department – "Kids are enthusiastic about the



activities



Once a week, the young patients meet up in an informal, relaxed setting and as they watch the movie, forget where they are and why they are there, immersing themselves in the story of the movie, emotionally connecting and identifying with the characters in it. "Each movie is carefully selected, never casually chosen" – explains Emanuele Guaia, movie program educator – "My task is to stimulate the discussion and create an environment where kids feel free to express their emotions knowing that they are listened to. I'd like one day to bring together all the kids that participated in the hospital's movie program over the years and contributed to its success and the significant results we are seeing today."





appointments

For the second half of 2017 our Foundation has scheduled further initiatives promoting science, research and education, engaging the academia, regulators and the general public.



The next Forum:

"Basic mechanisms of cancer immunotherapy" June 16, 2017 Auditorium USI, Università della Svizzera Italiana Lugano, Switzerland

For further information on our Foundation, its activities, past and future projects, science news, interviews, photos and videos, registration forms and media coverage of events please visit www.ibsafoundation.org.