

FEBRUARY 2017



IBSA FOUNDATION
for scientific research

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”**

FOCUS ON

**THE IBSA FOUNDATION FOR CHILDREN AND TEENS:
MOVIE PROGRAM AT THE LUGANO HOSPITAL**

ACTIVITIES

THE NEXT FORUM IN JUNE

APPOINTMENTS

Insights from the foundation

The patient at the centre - innovation and 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.



free session

IBSA Foundation Special Forum
14-ICML, LUGANO • June 16th, 2017

Basic mechanisms of cancer immunotherapy

BRUNO AMATI	IIT & IEO, Milan, Italy
FEDERICO CALIGARIS-CAPPIO	AIRC, Milan, Italy
GUIDO KROEMER	INSERM, Gustave Roussy, AP-HP, Paris, France
RONALD LEVY	Stanford University School of Medicine, CA, USA

The Forum is organized by
IBSA Foundation for scientific research



in collaboration with
Andrea Alimonti (IOR-IOSI, IBSA Foundation)
Franco Cavalli (ICML, IOSI)

Friday, June 16th, 2017 h 14.15-17.30
Auditorium USI
Via Giuseppe Buffi, 13
Lugano, Switzerland

For more info:
CGMKT
info@cgmk.it

Free registration
www.ibsafoundation.org



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.

 ISISA FOUNDATION
for scientific research

**"E-HEALTH" TRA BUFAL E VERITÀ:
LE DUE FACCE DELLA SALUTE IN RETE**

DECALOGO HEALTH LITERACY

Per Health Literacy si intende il grado in cui gli individui hanno la capacità di ottenere, elaborare e comprendere le informazioni di salute, i servizi e le competenze necessarie per prendere decisioni e compiere azioni informate per la salute (Paasche-Orlow, 2012).
Scarse competenze di Health Literacy comportano per i pazienti: scelte poco salutari, comportamenti rischiosi, minore capacità di autogestione e più ospedalizzazione.

1	Occhio alle fonti	È necessario prestare la massima attenzione all'estensione delle informazioni di cui stiamo usufruendo. Da privilegiare le pagine ufficiali di organizzazioni riconosciute ed affidabili. Le affermazioni che non fanno riferimento a fonti attendibili sono sempre da prendere con il beneficio del dubbio.
2	Forum e blog	Scenario del dibattito virtuale, in cui vengono raccontate esperienze personali, sono fonti particolarmente insidiose perché suscitano empatia ma non è detto abbiano affidabilità scientifica. La tematica della diffusione di informazioni è cruciale per la sua efficacia: è buona norma controllare la data di pubblicazione (dovrebbe essere sempre presente) dei contenuti che stiamo consultando. Anche informazioni su terapie o allarmi, corrette al momento della pubblicazione, alcuni anni fa, potrebbero non essere più attuali.
3	Controlliamo le date	Attenzione al funzionamento dei motori di ricerca "in" della nostra mente! Se ricerchiamo determinate parole ci verranno restituite pagine che le contengono, orientando i risultati ed influenzandoci. Da non sottovalutare il meccanismo di funzionamento di motori di ricerca e social network: il web ci propone, in prima battuta, informazioni che riciclano le nostre ricerche precedenti.
4	Non cerchiamo solo conferme	Bisogna tenere presente che tendiamo a prestare maggiore attenzione e a riporre maggior fiducia nelle informazioni in linea con quanto già sappiamo o crediamo. Un altro meccanismo psicologico da considerare è l'effetto della paura nella percezione delle informazioni: quando cerchiamo sul web dei sintomi (veri o presunti) siamo propensi a dare maggiore credito a informazioni "negative" suggeriteci dai nostri timori rispetto ad una malattia.
5	Attenzione a cosa percepiamo di quanto leggiamo	Nella comunicazione con il medico è importante chiedere di non parlare rapidamente o con termini troppo tecnici. E nel caso in cui alcune informazioni non dovessero essere chiare, è sempre possibile chiedere al medico di ripetere una seconda volta, eventualmente concentrandosi su uno o due punti chiave.
6	Non vergogniamoci di chiedere	Fareci accompagnare da qualcuno nelle visite più importanti può aiutare a migliorare la comprensione di quanto detto dal medico e a comprendere correttamente le azioni che dobbiamo intraprendere. Diminuisce la soggettività psicologica.
7	Non andiamo da soli dal medico	Prima di recarsi dal medico può essere utile ripetere quello che si è capito rispetto alla patologia e al percorso di cura ipotizzato. Averne la conferma di aver ben capito, fissare meglio nella memoria quanto appreso e saremo più attenti nel seguire le indicazioni.
8	Ripetiamo quello che abbiamo capito	Capire a cosa servono i farmaci che si prendono
9	Capire a cosa servono i farmaci che si prendono	Aiuta a seguire le indicazioni del medico rispetto alla loro assunzione. Se necessario, fare domande al medico sui rischi e benefici delle indicazioni ricevute. Finché non si comprendono bene le risposte.
10	La medicina personalizzata	Le informazioni aiutano a prendere decisioni in maniera consapevole ma affidiamo da quei siti che ci dicono come curarci e privilegiamo quelli che ci dicono in base a quali criteri devono essere assunte le decisioni mediche. L'informazione disponibile sul web non potrà mai essere pensata per il singolo paziente che deve sempre confrontarsi con un professionista da cui ricevere le informazioni e le cure adatte alla sua condizione.

Among these, **the elderly** who are more vulnerable to Internet “traps”, and **young parents** who often turn to the Internet in search of information and advice that could help them deal with the many issues that come up during the first years of a child’s life, from nursing to weaning, all the way to vaccines and infectious diseases. The guide will be distributed primarily through patient organisations that will make it available to their members by publishing the document on their websites.

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 IBSA Foundation for children and teens: movie program at the Lugano hospital

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

movie program, they often speak about it, including with us doctors, and look forward to this weekly appointment. It is not just a recreational activity. It is way for the young patients to process their own experience through the interactions with the other kids and the educator occasioned by the viewing of the movie. Rather than the choice of movie, it is the setting itself that being conducive to reflection and exchanges triggers such processing. Comments, feelings, thoughts and reflections expressed by the kids and anything happening during each session is then conveyed by the educator to the medical staff as contributing to an all-round view of individual patients.”

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.”*



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.