Ist International Meeting
Psychosocial Aspects of Osteogenesis Imperfecta
Lisbon – October 2012, 26 - 28

Fragile Bones, Unbreakable Spirit?

INFORMATION:
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Scientific Support

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THEMES & SPEAKERS

**Independance:** C. Potterton, Declaration of independence.

**Families:** M. Custódio dos Santos, Living with Osteogenesis Imperfecta, the impact on families. P. Marais, I. Marais & L-M Marais, Fatherhood, Partnership & OI. C. Almazán Peña, Unaffected siblings of children with OI.

**Language:** B. Ostarek & M. Barbero, The Language of Disability: How to talk about Osteogenesis Imperfecta.

**Quality of Life:** C. Hill, Development of a Quality of Life questionnaire for children with OI. A-M Vroom e.a., Bending without breaking. Quality of life in adults with Osteogenesis Imperfecta, K. Löwing, Everyday activity, important factors and quality of life in children and youths with Osteogenesis Imperfecta. I-L Andresen, L. Lande Wekre, Osteogenesis Imperfecta and Quality of Life – measured by SF36 and discussed in light of clinical experience. M. Hagberg & E. Åström, Perceived Activity Level in a Group of Children with OI Type I and IV.

**Sexuality & Relationships:** P. Marais, Sexuality, Self-image & OI. A. Ciliberti, Relationships and sexuality, prejudices and reality.


**Support:** U. Wallentin, Psychosocial support from inside the OI community. P. Fraschini, Social Networks in the Doctor – Patient Relation.

**Work & Energy:** A. Harsevoort, The art of balance - A description of 3 cases of adult patients with Osteogenesis Imperfecta. I. Westerheim, To work or not to work?

**Pain:** L. Barros, M. Custódio dos Santos, Workshop dealing with pain.

**Future Research:** T. van Welzenis, Brainstorm session, A look at the future, research questions, projects for OIFE and other OI support groups.

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**WELCOME!**

Dear Participants,

On behalf of OIFE and APOI we are very happy to welcome you here in beautiful Lisbon to “Fragile Bones, Unbreakable Spirit?” – psychosocial aspects of Osteogenesis Imperfecta, the first international event of its kind on this topic.

As you can see, we have put a question mark behind the title of our meeting to show that also the psyche can suffer from the impact of this condition. Acknowledgement of that fact is probably the first step in dealing with it.

Although the psychosocial aspects of OI have not been studied extensively, we feel the topic is of great importance to people with OI and their families. We are thrilled that so many have come together here now to share research outcomes, personal experiences and points of view. We hope it will contribute to both professional and social awareness as well as empowerment of people with OI.

As you can see on the opposite page, a broad and diverse range of themes is covered under psychosocial aspects, it shows how OI can have an impact on many aspects of the lives of both people with OI as well as those around them. While some effects have an immediate impact on the quality of life others can have long term effects for instance on the development of personality. It also shows how people with OI strive towards similar goals in life as most people; independence, (family) relations, sexuality and work. There can be obstacles on the road to achieve those like trauma, negative self-image, pain and limited energy but support and coping strategies exist.

We think that your participation will be invaluable to enlarge our common knowledge, to highlight the necessity to spend more attention on the psychosocial aspects of this rare disease and to stimulate further research and projects. We believe that when we; the people with OI, scientists and industry can join our forces in a truly “unbreakable alliance” that in the end, we can make it a better world for people with OI.

APOI and OIFE wish you all a very good stay!

Céu Barreiros
APOI’s President

Taco van Welzenis
Head Organizing Committee
Fragile Bones, Unbreakable Spirit?
Declaration of Independence

Catherine Potterton

Catherine is a 25 year old with OI who graduated from the University of Cambridge last year, decided to move out and live independently with two other Olers, and promptly broke her femur on the day she signed a contract for a flat in London. She created the UK youth weekend VOICE which helps young people with OI aged 16-30 work towards independent living.

In “Declaration of Independence”, Catherine uses amusing anecdotes from her own experiences and those of others, statistics and observation to tackle the subject of independent living, and the unique difficulties it presents people with OI. Addressing everything from why some parents don’t let go, why some young people don’t use a washing machine, and what to do if the electricity company asks you to read a meter that’s positioned above a door. Although “Declaration of Independence” is tongue-in-cheek, it is also a serious declaration to both parents and young people that it is better for everyone’s mental and physical health if young people live as independently as possible.
Living with Osteogenesis Imperfecta, the impact on families

Margarida Custódio dos Santos

Osteogenesis Imperfecta is a chronic clinical condition that affects patient and families. Although the impact of the disease on individuals and their families is determined by the severity of the disease, in most cases progressive dysfunction and progressive dependence is expected, imposing limitations to normal routines and influencing social and emotional development of both patients and families. Several authors recognize the importance of listening to families, so that effective interventions may be tailored to respond to their perceived needs and worries over the time of the illness.

This presentation will discuss some results of a study that aimed to understand families’ and patients’ experience of living with OI. These results referred to a sample of pediatric patients (N6) and their families (parents and siblings) (N10).

In this study we used a semi-structured interview to explore: (1) How patients and their families perceived OI (2) What situations do they referred as crisis moments through the experience of the disease; (3) What do they referred as coping strategies to deal with stressful situations (4) What are their needs and worries and (5) What do they identify as their perceived social network.

Results showed some differences among family members; highlighted some crisis moments that are usually less spoken; identified the most used coping strategies; and allowed the identification of parental worries. These results can be used as a good starting point to discuss effective psychosocial interventions and health professional attitudes that can promote family and patients adaption.
The Language of Disability: How to talk about Osteogenesis Imperfecta

Blanca Ostarek & Marí a Barbero

We live in the Era of Communications. It is now important for Osteogenesis Imperfecta patient associations to aim to acquire an appealing image that will enable them to better present themselves in the media in order to raise awareness about OI. And it is also essential that they choose an appropriate dialectic strategy to address the media and the general public. These are no longer times in which we should use vague, prudish and demeaning talk to refer to the reality of people with osteogenesis imperfecta: it’s time to talk about OI using concise, correct and uninhibited language. Only by referring to OI in this new way will we be able to put an end to prejudice and finally make way for a better understanding of the syndrome, as well as contribute to the social normalisation of OI’lers and their families.

As a starting point, we will explain the linguistic mechanisms of substitution and conceptual distortion that the use of euphemisms implies in the field of disability. Following this introduction, diverse dialectical options to refer to osteogenesis imperfecta will be analysed from a morphological and semantic point of view. Finally, several usage alternatives will be suggested, to contribute to the elimination of the social taboos associated to the condition and enhance the empowerment of the OI community.

This presentation is based on a paper that is currently being used by Spanish AHUCE training courses; it is now being adapted to the English language, among others, to encourage its worldwide implementation.
Development of a Quality of Life questionnaire for children with OI

Claire Hill

Background: Osteogenesis Imperfecta (OI) is a disease with varying severity affecting physical, social and emotional well-being of the child and their family. There is minimal evidence on how the paediatric OI population regard their quality of life (QoL) and currently no disease specific QoL measure. This presentation reports the first stage in the development of a disease specific quality of life measure for children with OI.

Methods: Initially; twenty-five qualitative interviews were undertaken with children, parents and health professionals, the main aim was to determine how OI impacts on the quality of life and well-being of children and their family. Purposive sampling was used to cover the diversity of the OI population (severity and age). Interviews were digitally recorded and transcribed verbatim. Significant themes were identified, extracted and organised, undergoing framework analysis. Secondly; two focus groups were undertaken with parents and children to identify further themes and validate those discovered through the initial interviews. The focus groups were video and audio recorded and transcribed verbatim. Previous themes were validated, any new sub themes were identified and organised within the pre-existing framework. The vocabulary used by the children and young people, guided by the main themes, informed construction of the items within the newly developed QoL measure.

Results: Six main themes were identified which showed similarity to other QoL measures, but the addition of being safe and careful demonstrated the need for a disease specific measure for children with OI. A 39 item questionnaire is now undergoing pilot testing, preliminary results of this testing will also be reported.
Methods: The clinical survey (including SF-36) in the Dutch Expertisecentre OI for Adults included 75 adults with OI divided into 3 clinical types – I, III and IV.

Results: It was found that the physical well-being of adults with OI came with an average score of 35, which is far below the standard score (50), while the mental well-being had an average score of 49, which lies above the standard score (42). For the total population correlation was found between the number of fractures, the number of wheelchair users and physical well-being. Type I correlates with length, weight, fracture, wheelchair use and both physical functioning as physical well-being. For types III and IV no correlation between factors and physical well-being was found. None of the factors correlated with the mental well-being of people with OI. People with type III score lower on the physical well-being and physical functioning than individuals with type I or IV. Adults with Type III had most fractures, the lowest bone density scores and all used a wheelchair.

Conclusions: It is noteworthy the subjective evaluation of the physical well-being and functioning among persons with type I and IV does not differ. Especially for type IV the severity of the condition is not related to the subjective evaluation of that severity. Whilst the clinical picture of people with type IV is more severe than that of people with Type I, they have a nearly identical score in the domains of physical well-being and functioning. The study also shows that the population scores equally on mental well-being to the Dutch population, while the physical well-being scores are much lower when both objectively measured by the medical specialist and subjectively evaluated by the patient.
Everyday activity, important factors and quality of life in children and youths with Osteogenesis Imperfecta

Kristina Löwing

Children and youths with Osteogenesis Imperfecta (OI) often display a complex and heterogeneous picture with fragile skeleton, fractures, curvature in the long bones, short stature, pain and limitations in mobility and everyday activity. The impact of those factors for the psycho-social situation and quality of life in the children and youths are to a less extent described. The aim of the study was to emphasize factors the children and youths with OI, thought were central in their life situation and for their quality of life. The study design was a descriptive survey. A consecutive sample of ten children and youths with OI (type I, III and IV) in the age 9-19 years participated. The participants were interviewed with a semi-structured questionnaire, including questions about school, leisure, hospital care, knowledge of OI, physiotherapy and furthermore they rated their quality of life. The everyday activity was investigated by Pediatric Evaluation of Disability Inventory (PEDI). The result revealed children with type III having a tendency for rating their Quality of life higher than those with type I and IV. To be short was experienced to be really difficult by many participants and some thought it was the most difficult part (Many participants experienced that short stature was very difficult). An important factor was to have a close contact with an orthopedic surgeon specialized in OI. Concerning physiotherapy most participants wanted goal directed activity focused therapy, with possibilities to learn and practice to be independent with for example toileting activities and dressing. Moreover, most participants also wanted pool training.
Osteogenesis Imperfecta and Quality of Life – measured by SF36 and discussed in light of clinical experience

Inger-Lise Andresen & Lena Lande Wekre

SF36 Results from a population-based study of Osteogenesis Imperfecta in adults will be presented. Ninety-seven participants aged 25-83 years (mean age 44), 56 women and 41 men were included. According to Sillence classification, 75 persons were classified as type I, nine as type III, 11 type IV and two were unclassified. Ninety filled out the SF36 form.

The OI group will be compared to an age and gender matched control group from a Norwegian population study. In addition, association between OI-type, gender, age, education level and different aspects of SF36 will be reported.

The results and the concept of quality of life will be discussed in light of a long clinical experience with people with OI.
Perceived Activity Level in a Group of Children with OI Type I and IV

Maud Hagberg, Eva Åström

Objectives: Swedish children with Osteogenesis Imperfecta (OI) are generally referred to the national OI-team at the Astrid Lindgrens Childrens Hospital, Stockholm. The children will undergo medical examinations but are also assessed by a physio therapist and occupational therapist. We have noticed that children with mild OI often report activity level problems despite normal Paediatric Evaluation of Disability Inventory (PEDI) ratings. We aimed to find a more sensitive instrument.

Methods: In order to find out how school aged children with milder forms of OI perceive their activity level the occupational therapist (1) chose to use the Activity Scale for Kids (ASK), a self-reporting questionnaire developed for children with muscular skeletal impairments and focuses on motor activities and ambulation. ASK has not yet been properly translated to Swedish so the purpose was also to find out if ASK could be an effective and client-centred instrument for evaluating self-perceived activity performance.

Results: The great majority had some problems in daily activities. Most common difficulties were with: Running speed, keeping up with peers and being able to participate in sports, especially team related sports. Only a few of the children with OI typ I reported no limitations at all.

Conclusions: The major part of children with the milder forms of OI experience some level of dysfunction in activity and participation. ASK seems to be sensitive for minor hindrance in the activity level and are therefore a feasible instrument for children with milder forms of Osteogenesis Imperfecta.
Sexuality, Self-Image & OI

Philip Marais

In this presentation I will study the topic of “Sexuality, Self-image & OI”.

I will ask myself the questions; What are the different views on Sexuality as this will impact on OI as specific disability? What role does the fragility of your body play, and that of your partner if the partner has OI and you do not? I shortly discuss protection measures from different viewpoints. I look at this from my perspective as adult and father with OI. I then move on to self-image and connect this to sexuality and try to look at the role self-image plays, what characterizes it? How do you know when it can improve and how to improve it.

My main conclusions are that the different aspects studied are not mutually exclusive and both are needed to function in a healthy relationship. Both are also possible.
SEXUALITY AND RELATIONSHIPS, PREJUDICES AND REALITY

Alessandra Ciliberti

What impressions, emotions, fears, attitudes does the word “Sexuality” move in each of us? What does sexuality mean for each of us and living with a sexual body and O.I.? We think that sexuality is a vital dimension of human existence “in se”, but also of the human being interrelations, i.e. human existence “per se” (Kant, 1790).

Sexuality is not a “category”, but a continuum-based dimension, that is a source of fears, crises and difficulties in the process of individualization from one’s own parents and from one’s own reassuring habits of pre-adolescence.

Crisis is not only for patients, young and adults with OI, but also for their parents and relatives.

Sexuality can be red also as sensuality, a way “to be in the world” and to get in touch with other people: with coetaneous men and women, physicians, physiotherapists and health workers.

Can our Association be a reference and listening point for pre adolescents, adults and parents of people with O.I.? We think so and thanks to our past experience both on our website and during our National Congresses, we experienced the importance to deconstruct our prejudices and concerns about sexuality thanks to comparison and meeting with people who told their stories and their lives that are unexpected and unique, as they are.
Influence of childhood experiences, signs of posttraumatic stress – Tendency for stress-related disorders?

Katerina Kavalidou

To date no research has been conducted on the exposure to the unique traumatic experiences that are related with the fractures in Osteogenesis Imperfecta and their impact on stress related disorders and PTSD symptoms. Previous research on children exposed to a variety of traumatic life events such as war conflicts, serious chronic diseases and cancer, have indicated the severity of PTSD symptoms and their role in the physical and emotional functioning of this study group. While parents’ experiential reaction on specific traumatic events may influence their children functioning and their reactions to stress related triggers, psychological interventions aiming at reducing PTSD symptoms within families experiencing a traumatic event, have been studied.

Considering the risk of anxiety disorders in populations with chronic medical illnesses and the unique symptoms of OI in terms of the recurrence of fracture experiences, proper treatment, prevention of PTSD symptoms in OI populations are necessary. Future research studies and methodology on PTSD identification and prevention among OI “sufferers” will be discussed.
Euphoria and OI – Are People with OI allowed to be Sad?

Rebecca Maskos

This presentation tries to shed light on assumptions about the euphoria which is frequently attributed to persons with OI. It presents ideas about how this is on the one hand a stereotype, on the other hand an observation that holds some truth to it. Trying to entangle the societal, psychosocial and innerpsychic aspects of happiness and OI, some ideas about the benefit of humor are presented – in the context of social desirability as well as in the one of innerpsychic coping of trauma and fear.
Panel discussion about “Happiness” and Personality in OI

Moderator: Therese Stutz-Steiger.
Panellists: Katerina Kavalidou, Eero Nevalainen, Catherine Potterton, Maren Rognaldsen, Taco van Welzenis

Several personality characteristics, such as euphoria / happiness, humour, creativity and intelligence have been attributed to people with OI. We ask ourselves if there is any truth in these claims. Could it be a self created myth or just how the external world perceives us? Could there be plausible explanations why certain personality traits develop stronger in people with OI? Can humour be a coping mechanism for instance or can a happy appearance be a way for a child to downplay the severity of its pain and lessen its feelings of guilt? And why would such mechanisms exist in OI and not so much in other disabilities that are also present from birth? Are the people that join an OI association an honest representation of people with OI or do the “unhappy people with OI” stay at home? If the average OI personality is indeed different from the average regular personality is “happier” than the best term to describe that difference? Can overstressing happiness and intelligence also become a burden for OI kids when they need to express their sadness or when they do not perform so well in school? A lot of questions indeed! After the panel has had its say we will include the audience in the discussion.

( P.S. And we do not expect to have all the answers! )
So in my experience and from what I observed during my life “inside the OI community” I am sure that (almost) any contact to “OI-peers” helps a lot and can have many beneficial aspects. My advice to every OI family is: Look for other people living in similar circumstances, bring your OI child in contact with other OI-children and show them that they are neither “alone” nor so very “special”. And – as a parent – enjoy the same feelings to share experiences with other mothers and fathers, learn from each other, live life with OI together and do go out and make the best of your sometimes “different” situation!

Even better, if OI people and their families can join (or set up and support) an organisation for OI-people – although this may be difficult due to the rarity, long distances. OI associations or groups, (even if nowadays they may often just be internet or “facebook”-groups – (in that case often having the advantage of many people and international relations) have a lot of extra benefits and advantages, like: lots of experience and knowledge about OI that is unknown in public and even in the medical world; valuable recommendations concerning therapy, life with OI, equipment. access to a big, complex network of professionals and “OI specialists” of all sorts; contacts to experienced doctors and therapists, clinics and personal knowledge about the (side-)effects of recommended treatments; people with a strong motivation to see OI as a challenge, not as a horrible disease that should be abolished eternally – we need to live with OI and can use any support!; they may organize or know about conferences, meetings, information on OI and life with it; opportunities to make friends with other OI-people and to mutual support; hotlines for information; knowledge about special features of this disability or about living with a disability in general (including social benefits in your home country); etc……

Come and join “the OI community” – benefit from it and share what you have and know!
Social Networks in the Doctor – Patient Relation

Paolo Fraschini M.D.

My personal experience using social networks like Facebook began about a decade ago through a friend with OI. This had nothing to do with medicine. Later a lot of young (and not so young) people with OI entered my group of friends on FB. Like every relation in life, a group of Facebook friends is a complex system in which you have both deeper and more superficial contacts, but the real difference is that you write things down, with all the implications connected to it. This interaction may increase the quality of the relationship with your patients, it may create a simple shortcut for clinical counseling, depending how you manage it. I’ve tried to search on Pubmed for positive and negative aspects, both from the patient and the medical point of view.

Facebook is the leading social network site, with over 1 billion users. Social media and the multimedia networks that they support provide a platform for youth and young adults to engage in different forms of creative expression, e.g. interactive blogging, photography and video documentation alongside real-world social action projects to promote health and to assist and evaluate research.

The use of Facebook and other social media networking applications is omnipresent across all ages and cultures. Facebook has finally begun to appear in the medical-scientific press. Today’s medical literature is focused on concerns of professionalism in young health care practitioners vis-à-vis the lay public as they continuously expose themselves through this online social medium. Prior studies have shown an increasing number of house staff accessing the site. While Facebook can be used to foster camaraderie, it can also create difficulties in the doctor-patient relationship, especially when boundaries are crossed.

Facebook hosts many of our patients, who are also exposed to the Internet and social media. Nobody so far has considered the opposite issue: that of physician invasion of privacy by "looking-up" a patient on Facebook during clinical practice for purposes of history-taking or diagnostic clues in situations where patients are too ill to provide needed information. We need to consider the ethical implications of privacy invasion in the current era of information technology. We need to acquire and maintain a certain level of "social media competency" to better debate the issues around Facebook and how we integrate on-line content with our patients' histories of present illness or past medical histories.

Personal and professional physician information is widely available on the Internet, and often not under direct control of the individual physician. The availability of such information has implications for physician-patient relationships and suggests that physicians should monitor their online information.

Paolo Fraschini M.D.

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The art of balance - A description of 3 cases of adult patients with Osteogenesis Imperfecta

Arjan Harsevoort

Introduction
Osteogenesis Imperfecta (OI) is a rare disease. In the Netherlands there is a centre of expertise for adult patients with OI. During a one-day visit to the outpatient clinic, the patient is visiting a core team; the advanced nurse practitioner, the orthopedic surgeon, the physiatrist, and the occupational therapist.

Study design
A description of 3 regular cases of adult patients with OI. We discuss the human functioning in the context of OI, using the bio psychosocial model.

Objective/Methods
In the Netherlands with a population of over 16 and a half million, there should be approximately 1100 -1500 patients with OI. We describe 3 cases of almost 200 adult patients who have visited our center.

Methods
We investigate clinical features by questionnaires, chemical measurement, bone density by dxa, cardiologic by echo, radiology by x-ray, lung measurement by spirometry, and further medical data are collected by medical history. Furthermore we describe the level of participation in society and the emotional and behavioural status of the patient. For this we use the Rehabilitation Activation Profile RAP, a systematic review widely used in The Netherlands in Rehabilitation Medicine.

Conclusion.
Adult patient with OI have specific problems, and need special care. Not only medical or biologic problems but also psycho-social care is needed in the treatment of adult patients with OI.

Key words: multidisciplinary, adult, bio psychosocial model
To work or not to work?

Ingunn Westerheim

Besides being the president in the Norwegian OI association, I work as a legal advisor in the Norwegian Directorate of Welfare and Labour. We deal with both unemployment issues and all the financial benefits during unemployment, sickness and pension. In the presentation, I will give you some thoughts about employment and OI.

- How does OI affect employment?
- How does employment affect our health and life in general?

The questions I want you to reflect about are:

- Are people with OI employed?
- Are there difference between countries and why?

In research studies from Norway and the US it seems as if a large number of people with OI are employed and that education levels are higher than normal.

- Are the employment levels higher among people with OI than other disabled people?
- How does having a job affect mental (and physical) health?
- What are the positive and the negative side effects of having a job and loosing a job?
- Do people with OI overcompensate and “work themselves to death”?
- How do we balance between work and life in general (family, exercise, health, social life)?
- Do people with OI need special career advice?

When it comes to the latter question it seems to me that many Norwegian people with mild OI tend to choose “practical” jobs, that can be physically challenging. Does this mean that they loose their jobs earlier? What should be considered when people with mild and severe OI get career advice?
Workshop: Dealing with pain in OI

Moderators: Luisa Barros & Margarida Custódio dos Santos

Based on input from participants the moderators will answer questions on this topic.
Fatherhood, Partnership & OI

Philip Marais, Izak Marais & Ly-Mari Marais

In this presentation I will study the topic of “Fatherhood, Partnership & OI”. I will ask myself the questions How do you become an Unbreakable fragile Father and Partner? And what defines fatherhood? And hat defines you, the lives of your children and your value as father and partner? And I will provide answers from my perspective as a father with OI. I identify the following important factors: Life’s realities, what is gained and what is lost in fatherhood and partnership, the difference between parenthood and fatherhood, some pre requisites for partnership. My main conclusions are that personally I recommend it, the benefits are great, the challenges are numerous and the legacy can be determined by you. Then my children Izak and Ly-Mari, aged 12 and 14 will provide their own view on life experience as the children of a father with OI, also looking at the positive and negative points as they experience it.
Unaffected siblings of children with OI

Carmen Almazán Peña

Imagine the following scene: It’s weekend, and Alex has a friend sleeping over. Slavi, Alex’s little brother, sneaks into their bed the following morning. The three of them hide under the bedsheets so that mum won’t find them. At least that is what they are thinking. Right on the moment when the mother is about to jump on them to scare them (as such a laughing bulge under the sheet is indeed suspicious) Alex yells “Be careful Mum! Be slow. Slavi is here”. This warning does not prevent them from playing even if the pressure that the mother can make on each of the children hiding under that sheet has to be different. Slavi suffers from OI and Alex is well aware of that.

In this study we want to focus on children and teenagers that, as Alex, are siblings of a child with OI. For a long time research regarding families of children with chronic diseases have been focusing on parents and have been paying very little attention on how their other children are coping. In fact, these other children have been called “the great forgotten ones” (Lizasoáin, 2009). By conducting semi-structured interviews we aim to explore, on two levels, what having a sibling with OI means. On the one hand we intend, through their knowledge and experience, to be able to develop educative tools that describe what it means to live and coexist with this pathology; and on another hand, we intend to understand what their needs are in order to create programmes of family intervention in which these children could be, for the first time, the centre of attention.
Brainstorm Session: A look at the future, research questions, projects for OIFE and other OI support groups

Taco van Welzenis

Our event here in Lisbon is unique. Never before was there a meeting focused entirely on the psychosocial situation of people with OI. Not much research has been carried out in this field, yet the organisers OIFE and APOI believe it to be a very important topic for all who are concerned with OI. People with OI and their families like to see their needs recognized and doctors and other care providers can learn how to optimize the care by taking into account the specific psychosocial factors that accompany OI.

With this session we arrive at the end of our meeting, yet we sincerely hope things are not finished now. On the contrary, we hope a positive force is created, call it “inspiration”, that we can all take home to continue our work on new and exiting projects in this field.

We offer this brainstorm session as a means to gather:

- Questions for future research, identification of areas that need further study
- Ideas for projects national OI societies could engage in
- Projects you would like to see OIFE work on
- Perhaps you feel inspired to work on a project after this meeting and you seek others to collaborate with – this is your chance to say so!

So this brainstorm session is mainly about wishes, ideas and dreams for the future. We will not look at what is possible, what can be financed and what resources we have. Those questions can be answered at a later stage. We are a mixed crowd assembled together here, which could provide a unique input from both the medical-scientific world as well as from those who live and deal with OI.