



Newsletter Number 17 Feb 2013

Editorial

Dear friends,

finally, we are very happy to present the new OIFE website thanks to innumerable hours work of our voluntary webmaster! You can visit us on www.oife.org .

In this issue:

Editorial

Report: OIFE Youth weekend 2012 in Norway

Introduction: The new Dutch OI - Foundation

Report: OIFE AGM in Lisbon

Did you know that...

"Fragile Bones – Unbreakable Spirit?" – OIFE's Topical Meeting that took place from Oct. 26-28, 2012 in Lisbon with more than 60 participants was a big success. The presentations can be found on our website. A report about OIFE's AGM which was held two days before, you can read in this edition.

Care4BrittleBones is the name of the new Dutch foundation with the purpose to raise funds for more medical research around OI. Here you find a detailed report by Dagmar Mekking, one of the founders.

So enjoy reading this newsletter!

Stefanie Wagner

OIFE Youth weekend 2012 in Norway

In June 2012 the Norwegian OI Association (NFOI) hosted the OIFE youth weekend in Eidene at an accessible holiday center located at an idyllic place along the Norwegian coastline - a report by Sigrid van der Mersch from The Netherlands:

First of all, it was a beautiful trip to Norway. Overall, we were lucky with the weather and we stayed at a great location owned and organized by the Red Cross. They offered nice meals three times a day, and the rooms were adapted for people in a wheelchair.

What I found very special this summer was to have a group of people together who share experiences in life although they are living in different countries. It was not only interesting to hear from others what their lives looks like, but it also was just a lot of fun!

Student Exchange program:

Would you like to **host** an OI-student? Please write an e-mail to office@oife.org if you can help. Thank you!



One of the highlights: an accessible boat trip along the Norwegian coastline

What I find special every time I meet people with OI, is how optimistic they are in life and how much humour they have. Having this spirit together for a couple of days and in a foreign country was an experience I will never forget.

The program in Norway wasn't too full and people were free to sleep a bit longer in the morning if they wanted to. The trips we made were nice and showed us more of the surroundings, by car as well as by boat!

What I would like to underline is if young people consider organizing an international weekend: That really isn't much work if you do it together with others from your country. We organized a weekend last year in the Netherlands and I found this very special. It is satisfying to see what these kinds of meetings mean to other people. Also, it is very much worth it: the contacts you get from it are great!



Care4BrittleBones – The new Dutch OI - Foundation

By Dagmar Mekking

Ideas?
Feedback?
Questions?
News?
Interesting stories
to tell?
Please write an e-
mail to
editor@oife.org

News in brief

There is a new
Romanian website:
<http://www.oiom.ro/>. For
the moment it is only
in Romanian but it is
planned to expand it
to English in the near
future.

Please inform us if
you change your e-
mail address. Thank
you!

Recently a “call for action” of the Dutch OI organization (VOI) has led to a new initiative: Foundation Care4BrittleBones. The sole purpose of this organization is to generate (more) funding for (more) medical research around Brittle Bones Disease to improve the quality of life of people with OI. This article provides more background and invites anyone who is interested to connect and join in by organizing activities that raise funds.

Why a new foundation? Why Care4BrittleBones?

Medical research can make an important contribution to a better quality of life for all people with OI. Think of the progress achieved by the use of bisphosphonates, which has quickly become a widely used treatment due to its positive effect on bone density and pain. There are many passionate doctors, who are keen to do more research around OI and have more ideas in which areas they would like to look for improved approaches to treating and preventing fractures and other symptoms of OI. Fact is, we would be able to progress faster in improving the quality of life of people with OI, but we are held back by the limited availability of funding.

However, in times of economic downturn, the reality is: Government grants are hardly available. Also the pharmaceutical industry has little market incentive to do more research on OI, given that it is part of the rare diseases and numbers of patients are relatively low (worldwide around 500,000). Where would the funds thus come from?

We, the founders of the Foundation Care4BrittleBones, Dagmar and Peter Mekking (parents of three children, of which a 6 year old girl with OI) and Jacqueline Hornman, are convinced that the solution lies in coming in action for doing fundraising ourselves and hopefully many people will join us for this! Many other rare diseases globally are using charity events very successfully to generate significant amounts of funding year on year for research. To our knowledge, in the Netherlands and in the wider Europe this was not the case yet for OI. Care4BrittleBones wants to change that.

How will Care4BrittleBones raise funds?

A significant portion of our income is expected to come from events of various kinds. Think of music, art, sports, entertainment, workshops, etc. There will also be various

OIFE's objectives:
*Representing its members on a European level
*Presenting the problems and needs of people with OI to national and international organizations
*Collecting and publishing information about OI
*Promoting research on all aspects of OI
*Supporting member-societies by the exchange of information and experiences

products and gift items available, via our website www.care4brittlebones.org

In the Netherlands Care4BrittleBones is recognized as charitable Institution and any donations are qualified for tax exemption ("ANBI" - Algemeen Nut Beogende Instelling). This qualification is generally applicable throughout the European Union and allows for tax exemption in all EU member states.

Core values of Care4BrittleBones

Everything we are doing is based on our core values: Positive + Inspiring + Innovative. Together with our partner organizations and voluntary workers we believe that these 3 terms truly characterize many people with Brittle Bones.

1.) Continuously dealing with setbacks, many people with OI develop a skill to live their life in an amazingly humorous, positive and strong way. They show tremendous resilience in the face of adversity and an ability to bounce back quickly, despite knowing that it's not a question of "whether" a new fracture is going to occur, but only "when". Until then, they get the maximum out of their lives!

2.) This spirit has touched and inspired us. There is a certain power, a mental strength visible in people with OI that allows them to transcend grief, frustrations and limitations and move on. This power lies in everyone. The fundraising and research projects of our Foundation will therefore be clearly linked to this theme.

3.) We have encountered great creativity and innovativeness in people with OI (typical for people with disabilities in general). Those who are "different" in some way often find themselves confronted with obstacles. By dealing with these challenges creatively, unexpected, surprising and innovative solutions can emerge, which can bring the overall outcome for everyone to a new, higher level. We want to utilize this power for our Foundation.

How will the funds be spent?

The Foundation, which was established in 2012, is 100% non-profit and will in the first instance focus on small-scale research, especially in the area of clinical research. By enabling a better understanding of various aspects of OI (such as Dentinogenesis imperfecta, hearing loss, etc.) tangible improvements should be generated for a better quality of life for people with OI. We have ambitious growth plans and our aim is to enable larger research projects as early as funding allows.

Donations

If you want to support us with a donation please send us an e-mail to office@oife.org

Thank you!

More information about the Foundation is now available on the website: www.care4brittlebones.org

Do you have feedback, or do you want to set up a project for fundraising for Care4BrittleBones, please feel free to contact us at: info@care4brittlebones.org.

OIFE AGM in Lisbon

By Laurette Paravano and Catherine Potterton

26 delegates and guests from all over Europe came to the 20th OIFE AGM. Here are some of the main themes and projects which were discussed.

An important topic: communication

Good news: the new OIFE website is now online! At the moment, it is only available in English and partially Dutch, but more languages will be added soon. Thank you to our webmaster, Rob van Welzenis, for all his hard work! Rob now plans to retire, so we should have a new webmaster in the near future.

Also coming soon is an OIFE Facebook page.

Our newsletter is still successful. Steffi is always looking for interesting stories to fill the newsletter.

We are also thinking about publishing a booklet about OIFE to help members understand what OIFE does what they can expect from it.

European Weekends

The last OIFE youth weekend in Norway was a great success; 38 young people participated, 11 from Norway with the rest coming from other countries. Such weekends are very important for OIFE; they are a perfect example of our Federation's aim to promote international exchanges among people with OI.

We have also been discussing organising an international weekend for adults. The event is still in the planning stages, but a committee has started to work on it and we hope to be able to hold the first event in the next few years.

Flying OI Experts

Every year, OI families from less developed countries carry out desperate searches for help, treatment and surgery for their OI child. Often, this involves having to go abroad, and only a few fortunate families can reach their goal of getting

expert OI treatment abroad, as it is very expensive, and few can afford the necessary (telescopic) rods, surgery, travel to and from the country, and accommodation both for the patient and their accompanying family members. Going abroad also fails to change the situation in their home country, and those less fortunate are still unable to access the necessary OI treatments.

One of OIFE's fundamental objectives and values is global spread and increase of knowledge about OI and its adequate treatment and care. We see it as being more efficient and equal to train local medical staff – doctors, nurses and physiotherapists – rather than to encourage individual families or patients to seek treatment in another country.

We have therefore begun to cooperate with clinics in countries as far afield as Albania, Russia, Egypt and Sri Lanka. We aim to help them organise internal or national training courses and workshops on the best OI treatment and care.

We try to contribute to the costs of such seminars and to offer subsidies for the travel costs of OI experts invited from known centres of expertise in OI. We also encourage existing OI clinics to invite colleagues from abroad to visit them, in order to spend several days in an OI clinic, during that time they can observe and learn modern surgical techniques and specialised OI treatment protocols.

Some Continuing Projects...

Topical meeting 2012: Psychosocial issues in OI

Some OIFE delegates have been very busy this year, acting as members of the organising committee of the topical meeting *Fragile Bones, Unbreakable Spirit?*

Student exchange program

As we recognise that each individual's situation is different, we prefer to not have a "standard protocol", but encourage our members to remember that the OIFE can – thanks to its wide network of friends and families who are part of national OI associations – help young students with OI to study abroad in another European country.

Fundraising

We are still fundraising. Only few OI associations (Norway, Germany), companies (Novartis, Alexion) and individuals supported OIFE this year, both with general donations and also with purpose-specific donations (for example, to fund Flying OI Experts).



Beyond Europe

The Latin-American OI conference in Quito, in December 2011, was a big success (see OIFE Newsletter 15th March 2012). It was an important opportunity to teach Ecuadorian (and South American) doctors about OI treatment and care.

The association Padrinos-OI is continuing to sponsor 90 OI children and young adults from less developed countries, with a particular focus on South-American countries.

Our AGM had to be very “efficient”, as we had only a small time frame and many matters to discuss. We were, however, able to finish on time to start the topical meeting! Our next AGM will take place in April 2013 in Paris, and will coincide with the national French OI conference.

Did you know that...

...OIFE has got two new members since 2012? With Romania and a first OI society from Moscow/Russia 25 countries form the OI Federation Europe!