



Osteogenesis Imperfecta  
Federation Europe

# Newsletter Special Edition OIFE 20<sup>th</sup> anniversary



## Editorial

What a nice coincidence: this is the 20<sup>th</sup> edition of OIFE's newsletter that has been started and first edited by OIFE's former vice-president and longtime-delegate Filip de Gruytere from Belgium. And with this special edition we are going to celebrate the 20<sup>th</sup> anniversary of the OIFE.

In September 1993, on invitation of the UK "Brittle Bone Society" and after years of hopes, ideas, discussions, consideration and preparations of our "Founders", Delegates of 7 national OI associations and some observers from other countries met in Oxford.

Days of excitement, laughter (and some tears) followed, we all were happy and optimistic about this new step ahead together as "European Federation".

But nobody would have imagined that (only) 20 years later the OIFE has come so far: in 2013 we do have more than half of all existing national OI groups worldwide as our members. A close network of incredibly creative and active volunteers, people with OI, their friends and families and hundreds of doctors, researchers and all kinds of other professionals do regularly get together, cooperate, share experience, knowledge and precious time.

Osteogenesis imperfecta is one of many rare disorders, life with OI has its challenges and sometimes is really hard and difficult. But: it brings people together! And together we have overcome many obstacles so far and will continue to grow and to get stronger.

"Thank you, merci, bedankt, grazie ..." to those few wonderful people who started and "made" the OIFE! Some of them have personally contributed to this newsletter and share some thoughts and feelings below....

**Ute Wallentin, OIFE President**

## When OIFE touched my heart – personal impressions by founding members

Lidy van Welzenis, The Netherlands:

“During the time Rob and I were active in the OIFE-world we were able to visit many OI-societies in Europe and abroad and we always felt welcome to participate. Usually we could communicate well, sometimes using hands and feet, and a few OI-specific words such as “fractures”, “plaster”, “rodding” and “nail”. It happened several times that someone trusted me a personal life story, which will stay in my heart forever.

We also realised regional and traditional differences at those meetings: roaring music and dance evenings in Spain, champagne in the morning at a presentation in France, an elaborate dinner in Belgium. With respect, we enjoyed them all. It struck me that so many OI-societies had been initiated by a mother-of-a-child-with-OI.

But if you ask me what has touched me most, that was the GALA-Dinner at the celebration of the 20<sup>th</sup> anniversary of the Norwegian OI-Society in 1999. Why? While I was packing for our trip I was thinking: Gala? How much gala will it be? It was real GALA! Everybody officially dressed up, ladies in real evening dresses, some of them in a wheelchair wearing high heels. So beautiful, so happy! So unique too. And why not?

Remembering this event made me realize that if the guests of that evening did not have OI, or a relation with it, they would probably not have had such a splendid and proud evening in their life.”

Rob van Welzenis, The Netherlands:

“First of all it happened on different occasions and in various countries that ordinary OI persons approached me and thanked me for what I did for the OIFE, because it meant so much to them, in very heartwarming words. That touched me deeply, because I was never aware of doing anything very special, just trying to do what needed to be done. It proved to me that the OIFE meant more to them than just an umbrella organisation, they felt they were recognized in a larger community. A stronger stimulus was not possible. In this respect I was emotionally repaid richly. The OIFE gave me more than I put into it.

Another thing that struck me many times was the special and friendly atmosphere at any OI meeting I ever attended. It is difficult to explain what is so special about these meetings, but it is a general feeling of mutual understanding and compassion. I also remember telling a high ranking European official in Brussels that the OI community could serve as an example for the community as a whole. He asked me why and I said come and see for yourself, but as far as I know he never did. Then there is the this anecdote about how I learned to think European. At one of the first OIFE AGMs a discussion emerged between one of the Scandinavian delegates and a southern European delegate (I know exactly who those two persons are, but I do not want to mention their names). After about one hour of fierce debate the conclusion was that they very

much agreed on the issue at hand, but because of their different cultural approaches had totally misunderstood one another. That was a wise lesson for the chairman of that meeting. And last but not least I must mention the numerous friends we made in the OI communities all over the world."



*Lidy and Rob van Welzenis*

Yvonne Grant, UK:

"I write to you on behalf of my Mother Margret to say how deeply touched she was to receive your beautiful card and photographs of your recent celebrations of OIFE. How time flies.

As you are all aware the Brittle Bone Society started away back in 1968 here in Dundee. Time and tides move on, The BBS is contact with many people and various different organisations all helping to promote the work of Osteogenesis Imperfecta and its associated conditions throughout the world.

The needs of all our members change almost on a daily basis, with this comes varying challenges to all those effected by this sometimes harrowing condition and all that this entails.

We as a family will always be grateful to all of you who welcomed us with open arms at your conference many moons ago ( for the moment) the name of the venue escapes me. But what I can remember is that everyone came to Mum and Dr Colin Paterson asking for their knowledge and understanding, including the medics who were present at that time. Rob and Lidy and Taco who was only a youngster at the time and Clementine, Jean and Vern van den Boorn who met us at the airport to take us to the meeting, then gave us hospitality spending a delightful time being shown round its famous sites by the family. Vern at that time was learning English and to his delight my Dad said to him "Sit on your Bum" to this day when we correspond we always end with that phrase! . We were also introduced to UTE and a joy that has been. We have attended

two meetings in Holland.

We have fond memories of Rob telephoning Mum at various times when he and others were trying to establish the OIFE in Europe and we are so pleased and delighted that this has come to be.

Rob Lidy Taco and Van den Boorn Families have visited our home on several occasions mostly when the children were younger, we have visitors from all over the Globe visit our home, from Europe, Asia, Australia America and other parts too many to list

We have had various people from OIFE at our various conferences through out the years, all of them different and challenging to all who visit us here in the UK. But one thing remains firm, we are all joined by a condition called BRITTLE BONES or Osteogenesis Imperfecta.

All our Society's and Associations are growing in strength but lets hope that one day a cure will be found so that no more bones will be broken.

I would love to visit again and who knows what is around the next corner!

We The Grant Family wish you well for many more years to come.

Congratulations!"



*The Grant Family in the front from left to right: Yvonne, Margaret and her husband. The photograph was taken at our recent Wishbone Day Launch*

Marcella Zingales, Italy:

"I have to mention my emotion when in 1987 in Pavia I met for the first time representatives of all the OI associations coming from all over the world: USA, Netherlands, UK, France, Germany and so on. We were so pleased to share our experiences and our aims and we talked and talked till two o'clock in the morning and when two days later we left our farewell was to found an association that put together the aims of OI people. So I think that OIFE

was born from hearts touched by the hope of

OI people.

The 20<sup>th</sup> anniversary of OIFE is a great success because it is the realisation of our aims.”

Dear Ute I'm so grateful to you for your work and I wish you all the best!”

