5th Cutis Laxa Days

ANNECY (France) 5 - 8 MAY 2016

Speakers' and Attendees' Testimonies

Mr PAUL DE BREM, Moderator

I was happy to meet people, sufferers and members of the family, open-minded, smiling, courageous, whose only aim is to keep on making the most of life.I was so glad to be of help throughout your Days. The encounters I was able to have, the human depth of the exchanges, your satisfaction for my work, are my reward.

Mme DOMINIQUE MULLER, Interpretor-Translator

Just returned from France where I translated / interpreted for a group of people who live with an extremely rare condition called Cutis Laxa. This is a disorder of the elastic tissues so the most obvious expression is in the skin: young kids look old, their face is drawn. The disorder can also affect the heart, lung, blood vessels, eyes and more. The only charity / association for this is Cutis Laxa Internationale: they've been going for 15 years and have connected with 300 sufferers worldwide - it's that rare. So it was even more important that 17 of them were able to meet to get a chance to find out about each other, recognise each other and hear about the latest research etc. A fabulous few days where similarities and differences were assimilated and the human being exalted. Seeing the prepubescent girl gradually loosen up and feel confident to express herself --- dancing; observing the exchange between a much older sufferer and the parents of a young boy --- suddenly able to see a future for their kid; being around the explosion of a new transatlantic friendship that is changing the lives of two young women; whoa .. it was truly awesome to be able to be the oil in the mechanics of this organic network. Lots of love

Dr BERT CALLEWAERT, Researcher, Speaker

Thank you for your terrific organisation of this conference.

Dr MiCHELLE MURROW, Study Coordinator, Speaker

What a success it was! I can't tell you how lovely it was for me to meet the families who attended.
It was an experience that enriched my life on a personal level, and will also enrich my future professional life as a genetic counselor.

Dr MARIE-HELENE BOUCAND, Doctor of Philosophy, M.D., Speaker

I am back from "Cutis Laxa land" …… two days of paradise

Mr ALAIN BOISSEAU, Behaviour Psychologist, Speaker

His lifelong man will suffer from a paradox : the need for being part of and at the same time the need for specificity. He will spend his life developing either the signs, the tokens of belonging, or the marks of his specificity. Batson says that a double constraint makes you mad. Thus how can you manage, especially when one of this specificities is one you could happily do without, that is carrying a Cutis Laxa? My Master says " Do not mock, do not deplore, do not curse, but understand » It is the secret that leads to Joy.

On the 6th and 7th May, alongside the Lake of Annecy, I deeply felt this paradox : my specificity, being almost anonymous in this group where people knew each other, not knowing much about that CL disorder, my perception of the rest of the world while listening to foreign languages … But I quickly felt my belonging to the human world through the warmth and quality of the people attending. I could feel like being in a family thanks to the relevance of the scientists who knew how to place at my, at our, disposal all the latest and accurate scientific knowledge on CL, like big brothers who very kindly share their knowledge with the youngest in the evening during the diner.
And what about those moments of conviviality, all united with only one aim : have a good time and share. Thank you to all of you.

Dr PASCAL SOMMER, Researcher, Attendee
This Cutis Laxa Meeting is a unique opportunity for a researcher

A Cutis Laxa meeting is always a unique moment. As in every meeting, I can measure the intensity of each person's feelings, between anxiety and the pleasure to meet again, between sharing peculiarities or exploring new territory for those attending for the first time.

What first struck me during this meeting concerns the way genetic research is carried out. Knowing the affected genes changes our gaze. It is no longer a simple situation revealed via a diagnosis which, when all is said, is quite fragile (loose skin) ; It is the possibility to gather people together. And having the possibility to talk with them about their problems. Thus, each voice can be heard while, together, the voices provide the strength necessary to build a story. And now we, the researchers, can work on this story. And thanks to this shared experience we can now move forward.

Researchers are no longer facing rare, heterogeneous, peculiar cases, but families newly built through a shared genotype. Thanks to knowing the gene we can recognise common characteristics that are now understandable.

Nevertheless, identifying a mutated gene does not explain everything. As in all families, there are differences; we must understand them. It did us a lot of good to neglect genetic and medicine for a little while to focus on behavior instead. We must work on mind and sensori-motricity when there is distortion in the body. We must search for each one's hidden resources. It might not change anything for the treatments of pathologies, but it can change the gaze on oneself and on others and the efficiency of future solutions.

Of course, the researcher is always energized by finding. Finding a way to cure, or at least to soften the constraint of a body which does not bend to the usual codes of mechanics. This was touched on during the meeting. Doors are opening. We hesitate, we dare not believe in it, we want to verify and validate. It takes time, too much time. But we progress. Maybe too slowly, but nonetheless we progress. And we need the energy stored up during those meeting to nourish our researcher's drive, build our tests and develop projects that could sometimes be unprofitable, but sometimes winners. And so to conclude, thanks to this beautiful community, and thank you to this incredible Boiteux Family who organized this wonderful moment for us.

Mrs MARIE-CLAUDE BOITEUX, Chair of Cutis Laxa Internationale

Dear Families, Dear Friends, Dear Members and Donors, Ladies and Gentlemen,

Before ending this day, I first want to thank Mr Paul De Brem for showing an interest and accepting to moderate this day. Thanks to the "Crazy Scientists" who took care of the children so well this morning with adapted scientific activities.

Thanks to all the speakers, Dr Maxime Etienne, Pr Zsolt Urban, Dr Bert Callewaert and Dr Romain Debret who came to share their knowledge and the findings of their research. Thanks to Marie-Hélène Boucand, Alain Boisseau and Yanne Louys-Elizon for leading the moments of exchange and sharing this afternoon. Without them I am not sure words would have been expressed so freely. Thanks to the professionals who attended. It moves me that they took some of their so precious time to come and meet us. Thanks too to Groupama whose Foundation and local Federations enabled us to provide substantial financial support this year to sufferers who wished to attend, wherever their home countries are.
And a special Thank You to my sister, Dominique Muller, who came from London to help our English speaking guests with understanding today's presentations and exchanges. She is also the one who reviews all my English translations since we set up Cutis Laxa Internationale. Many Many Thanks Domi.

Thanks to all of you for coming and sharing these days with us. Today over 60 people concerned by Cutis Laxa gathered together in Annecy. For many of you it is the first time you meet other sufferers and I know how moving it is. For others it is joyful to have the occasion to meet again. 12 countries are represented: Algeria, Germany, Australia, Belgium, France, Great Britain, Lebanon, Mexico, Mongolia, Sweden, the USA and Venezuela.

My thoughts are also with those who wanted to come but who have been put off by the tragic events in Paris and Brussels.

The spring of 2016 will leave great memories in our minds as there have been 2 meetings, such important moments for sufferers.

The first one was held in the USA with the clinics organised by Pr Zsolt URBAN and his team from 17th to 19th March. This year, they were specifically dedicated to the Autosomal Recessive Form Type 2. As ever, those days allowed isolated patients to meet other patients, other families and share a magical moment together. I want to share with you some comments from participants to those American days :

« I have left feeling like I got answers »,
« I have never met anyone with Cutis Laxa before, and just knowing that there are people out there that are so similar to me is so reassuring. »
« We spent the evening comparing notes, cataloging our various unique features and surgeries. Nice to be with people who understand. »

And I won't forget to tell you how those days allowed a 7 year old little boy to understand where his disorder comes from. This is how he explains it to his elder brother: *« Mommy has the Cutis and Daddy has the Laxa, put them together and you get me!»……*

Today we share the 5th Cutis Laxa Days and I know they will remain for all of you a precious moment of sharing and gathering knowledge about the disorder. We had a rich day full of information on research progress and a moving afternoon full of exchange and emotions.

We still have nice moments to share: tonight, let's have a relaxing evening with the diner-cruise on the lake ; Tomorrow morning we will work again a little while with the Annual General Meeting, to which by you are all invited, before a pleasant visit of the Old Town, by way of a "Treasure Hunt".

So see you later and I wish you all a nice end of day.
Marie-Claude BOITEUX, Présidente