It is a great honour to address the families present here at this World Conference on Rett Syndrome.

It is also a great pleasure to be here in New Orleans, la Nouvelle Orléans, as we say in French. We could be all speaking French all over the world if Louisiana had not been sold by France in the past !

Thank you for the choice of New Orleans which has been through so much drama with the hurricane and the floods and has shown so much courage. For us, New Orleans remains a symbol of advocacy for a cause.

First of all I would like to excuse Dr Gerard Nguyen, former President of RSE and one of the main organisers of the previous World Congress in Parisin 2008. He is very sorry, busy with the European Commission evaluating research projects and also has commitment playing in a theater in his town a piece of comedy. He has transmitted me a message to all the parents, saying parents are to be the “mayonnaise” between policy makers, researchers, health professionals, care givers and our girls. And this gives us the responsibility and the power to transform our drama into something more powerful

I am Secretary of Rett Syndrome Europe and mother of a 16 year old and my colleague Thomas is also on the board of RSE and on the board of the French association and father of a six year old daughter.

On behalf of Rett Syndrome Europe, we would like to thank the organisers of this congress, IRSF, and all the researchers and experts making it happen in New Orleans.

The previous congress in Paris mixed scientists, doctors and families and associations. We think this kind of openess benefits all parties in the era of the internet.

It is a real satisfaction to see research is so vibrant and we can only be thankful to scientists and clinicians for their commitment. Research on genetics is very active, the program of this congress proves it.

But let’s face it : RTT is a multidisability condition and the challenge for families is day-to-day living and everyday care, with numerous issues like feeding, swallowing problems, epilepsy, orthopaedics and spine surgery, osteoporosis, disrupted sleep, adaptative equipment and devices, communication difficulties for their child and with their child, education and how to give them the best possible life.

So, in my mind, family associations have to be careful to keep means to support families on those issues and to encourage research into them. Family outcomes and patient driven research should not be the neglected part of any modern research plan. It is in the International Rare Disease policy !

Charting the course is the title of this Congress. I wondered how to translate it in French, then I remembered : about 12 years ago, one morning, I heard on the radio, while having breakfast after another night without sleep, I heard a journalist interviewing a sailor during one of these famous transatlantic sailing race. And this sailor was saying : “well, the sea is very rough, waves are very high, I sleep only ½ hour now and then, it is a hard challenge…”. And I thought to myself : well how long is it that we have not had in our family a proper night sleep ? A week ? A month ? A year ? Several years maybe, like maybe many of you. And the sea is very rough over here …in my life. So I thought : well, I am a hero, like this sailor and I think we, the families, are heroes, we are all heroes.

Thank you for listening