EDRIC Update

January
2013

Ambitious aims for 2013: Going global to plan an EDRIC Experts' Conference

2012 was a momentous year for a small band of Thalidomide survivors who, some years ago, imagined building an online network that would bring together the many, often isolated, small organisations and groups that supported people with limb deficiencies.

Their dream of utilising the rapidly evolving social internet to do this became a reality with the launch of the DysNet Limb Difference Network.

As of the beginning of 2013, there are now 19 European-wide member organisations of EDRIC, the umbrella organisation established to promote a powerful voice for people linked together by similar disabilities.

The EDRIC members' meeting in September 2012 brought all the organisations together under one roof in Malmö, Sweden, and cemented relationships, old and new, and confirmed the belief of the EDRIC board that people from different nations did want to join together and find strength in numbers.

In 2013, the plan for EDRIC is to continue this expansion at a steady and manageable pace, across continents and languages, embracing limb deficiency and limb loss groups of all types, to create a global, powerful movement that will improve the lives of everyone living with limb disability.

The big project for 2013 will be to apply for an EU Conference Grant of €60,000 in order to bring together patients, medical experts and industry specialists together to share knowledge and engage with each other.

Patient empowerment and participation is a growing theme and EDRIC plans to take this further this coming year. Too often, our members must travel long distances to find the right care or are faced with doctors who do not understand how to treat people with missing or shortened limbs.

It's time to change this and EDRIC is hunting the globe for experts to join us all at the conference in May 2014. We need your help, your knowledge and your participation to make it happen.

Read how you can help make the conference a success on Page 5.

EDRIC welcomes three new Board members

Last year we began expanding our board with the addition of Charlotte Fielder MBE, who has raised many thousands of pounds for Reach.

We are now proud to announce three further new board members in Gernot Stracke of HICOHA in Germany, Michaela Moik of Contergan Austria and Sal Giambruno, of Raggiungere, the Italian Association of families of children with limb deficiencies.

Gernot Stracke is a board member of HICOHA (Hilfswerk für Contergangeschädigte e.V. in Hamburg and Schlewsig-Holstein) a German thalidomide organisation.

Gernot Stracke

He is married and has two children.

Gernot works as sales manager for an international consulting company with a strong focus on IT-solutions and is also instructor for speech recognition systems for people with limb deficiency and other physical difficulties.

Michaela Moik is a thalidomide survivor and one of the founders of the Austrian Thalidomide self-help group.

Michi Moik

She works as a social worker in the Youth Department of Vienna and has three children.

Sal Giambruno is a longtime board member and past president of RAGGIUNGERE, and past president of LEDHA, a federation of 32 associations representing various disabilities.

Sal works as sales manager for the touch systems division of a large international corporation.

Sal Giambruno

EDRIC chairman, Geoff Adams-Spink, said, “We’ve seen so much success in 2012, with the launch of DysNet and our members’ meeting, we needed to consolidate our leadership structure. This will ensure the future smooth running of EDRIC as we continue to campaign for improved access to health, work and creating better lives for individuals coping with limb loss, whether congenital or acquired through amputation.

“All three of our new board members have many years of involvement supporting people living with limb differences and I am sure they will bring their diverse and valuable knowledge to benefit EDRIC.”

EDRIC would also like to say a huge thank you and a fond farewell to Klaus Becker, who has stepped down from the board. We wish him well in the future.

RareConnect.ORG
A PARTNERSHIP OF EURORDIS AND NORD

is YOUR forum

DysNet/EDRIC's community forum is hosted by RareConnect, set up by EURORDIS, the rare diseases organisation of which we are all members, and NORD, the North American rare disease organisation.

EURORDIS
Rare Diseases Europe

Being part of RareConnect means that we have experienced moderators and online managers who maintain and monitor the forum and who are on hand if a user encounters any difficulty.

NORD

Join the conversation on RareConnect at http://www.rareconnect.org/en/community/dysnet

If you need more help email Tania Tirraoro


I want to...

Tell my story >

Start a discussion >

Meet other members >

Learn about the disease >


Rob Pleticha & Marta Campabadal of Rare Connect

Five reasons why you should make RareConnect your community

1. If you do not have a safe, moderated forum of your own, the RareConnect DysNet forum is an ideal opportunity to make it a place for your members to meet online and have extended discussions over time in a way that is not possible on Facebook.
2. We can only make it a thriving community if you encourage your members to take part and connect with other people with similar conditions who may be feeling isolated and who would appreciate the opportunity to discuss their issues or share their knowledge.
3. As EDRIC members, the RareConnect forum is an integral part of your organisational benefits and a way that we can learn what your members are interested in. This will help us highlight issues and improve lives. Together, we are stronger.
4. It is a great way to extend knowledge of your organisation and its work across the world. There are many people who may benefit from the knowledge, tips and ideas that you have.
5. It's a virtual meeting place just for people like you - a place you can call your own!

Meet our Patrons

Alison Lapper

"I'm really pleased to become a patron of EDRIC. I wholeheartedly back the EDRIC aim to share the knowledge and expertise that people with limb disabilities have gained as they live independent lives. Bringing together people and resources in this way can only strengthen our voices."

Alison Lapper MBE, renowned British mouth painter, became our first patron.

Ms Lapper has significant limb deficiencies (phocomelia), and is best known for the statue depicting her nude and pregnant, that graced the fourth plinth in London's Trafalgar Square.

An enormous replica of her famous statue was featured at the opening ceremony of last year's Paralympics.

Bonnie St John

American keynote speaker, Bonnie St John lost a leg at the age of five.

She was the first African-American ever to win Olympic or Paralympic medals in ski racing, taking home a silver and two bronze medals in downhill events at the 1984 Paralympics.

NBC Nightly News named Bonnie, "One of the five most inspiring women in America."

"This is something so close to my heart. I'm excited at the prospect of working to raise awareness and inspire others with disabilities to achieve their goals."

Mikael Anderson

Swedish motivational speaker, Mikael Anderson, was born without arms or legs but was not deterred from achieving his own dreams.

Mikael has inspired many people by talking about his own approach to problems and how he overcame his lack of confidence and physical challenges to transform his life.

"Becoming a patron of EDRIC will give me an opportunity to help more people with limb deficiencies achieve the best they can. Sometimes we are prevented from gaining success by our mental attitudes rather than our physical limitations and I hope that by being an EDRIC patron, I can help show people just what is possible."

HOW YOU CAN HELP MAKE A SUCCESS OF THE EDRIC EXPERTS' CONFERENCE

To make our 2014 Experts' Conference a success, we need your help.

Do you know a medical professional, researcher or innovator in the field of limb deficiency?

We need them to share their knowledge with others and to do that, we need to make contact with them.

We're asking you to pass their details to us so that we can get in touch with them.

If you have any ideas for seminars you would like to see, please let us know.

We're anticipating that the conference is likely to be help in Stockholm in May 2014.

EDRIC members will, of course, be invited to join us and share your own experiences - we, after all, are the real experts!.

Please help us by sending any contact information you have for any experts you know to tania.tirraoro@edric.eu

Have you taken the Limb Loss Lifestyle survey?

We launched the survey in November and it is scheduled to run for another few months.

The survey is currently available in French and English. If you can help us translate it into your native language, please get in touch.

This research can give us important information for future campaigns and lobbying to improve the lives of people with limb deficiencies so do please take the time to complete it.

You can find it at http://fluidsurveys.com/surveys/edric/elld-survey/

EU Accessibility Project

EDRIC is involved in an exciting EU research project to design accessible user interfaces.

The project is called Inclusive Interfaces for Smart Environments (INCISE) and involves making products and user interfaces accessible for the broadest range of people, including those with physical impairments.

The project is being co-ordinated by academics at the German University of Bremen, which aims to develop assistive devices carried or worn by the user, which enable them to use consumer electronic products more easily.

European Limb Loss Day

Raising awareness of children and adults living with limb loss & deficiency across Europe

EDRIC in 2012, year joined the UK's Associate Parliamentary Limb Loss Group and took part in European Limb Loss Day.

We're really pleased that some of our members marked the day, including Reach and TAI Onlus.

EDRIC took responsibility for establishing a central European Limb Loss Day website and we made some great new contacts.

We hope to include many more of you in 2013.

EDRIC marked the day with board member, Charlotte Fielder, taking part in Paralympics GB's SportsFest event aimed at getting young people with disabilities into sport.

She spread the word about EDRIC and had a great time, as you can see by the photos!

Images: Gary Fielder

RARE DISEASE DAY®

28 February 2013

www.rarediseaseday.org

Rare Disease Day is coming up fast. As dysmelia of all types are rare diseases, you have an opportunity to take part and highlight your organisation.

Do you have any members who would be interested in telling their story to us that we can use on the DysNet site for Rare Disease Day?

We are also happy to advise you if you wish to use Rare Disease Day to highlight your work with the media in your country.

If you have a member case study we can use, please send it to us as soon as possible.

You can access RDD materials at www.rarediseaseday.org

Rare Disease Day

Our EDRIC Community

EDRIC Member Listing

EDRIC

DysNet

An Organisation for People Affected by Limb Differences

Föreningen för de Neurosedynskadade
The Swedish Thalidomide Society NGO
A Associação de Talidomida da Suécia

The Thalidomide Trust
www.thalidomidetrust.org

Reach

"RAGGIUNGERE"

Contergan Austria

assédea
Association d'étude et d'aide aux enfants amputés

Nesos

AVITE
www.avite.org

AVBS

Irish Thalidomide Survivors
thalidomide survivors

DNTF

HICOHA
Hilfswerk für Contergangeschädigte e.V. Hamburg

TAR

TAI Onlus

Contergan NRW

thalidomide society

Find DysNet at www.DysNet.org. Are you following DysNet on social media? Click the image to find us online

EDRIC (European Dysmelia Reference Information Centre) is registered in Stockholm as a Non-Governmental Organisation (NGO) under Swedish Law. Registration Number: 802444-3015.