



## Chromosome 18 Registry and Research Society (Europe)

Charity Number SC0403- -

The Chromosome 18 Registry and Research Society (Europe) is a new European organisation set up to cater for the specific needs of those with Chromosome 18 disorders, their parents, relatives and siblings. As the name implies, it is closely associated with the Chromosome 18 Registry and Research Society in San Antonio, Texas, as well as having ties to the associations throughout Europe that deal with all rare chromosome disorders (such as Unique in the UK, Valentin-APAC in France and Leona e.V. in Germany). It was registered as a charity in Scotland in April 2009.

Two of the founding members attended conferences run by the Chromosome 18 Registry and Research Society in the US. They were so convinced of the usefulness of such meetings that they want to hold similar ones at different locations in Europe every two years for those who cannot travel to America. Such conferences and workshops will be for people with the disorders, involved family members - carers, parents, siblings and grandparents - together with the professional clinicians, geneticists, therapists, educational experts and other professionals who specialise in relevant disabilities. To make the conference accessible for people from across Europe we plan to have simultaneous translation into the languages that participants request when registering.

Joining the Chromosome 18 Registry and Research Society (Europe) will give access to the web list-serves, which provide a place where those affected can discuss important issues, ask questions, and share their knowledge. Presently there are list-serves for the following groups: 18p-, 18q-, Ring 18, Tetrasomy 18p, relatives of individuals with chromosome 18 abnormalities and one in the Spanish language. The intention is to establish more list-serves in European languages other than English and Spanish so bringing this mutual help and support to all of Europe.

So far we have launched a web-site (<http://www.chromosome18eur.org>), started to recruit members across Europe and are beginning to seek funding and organise the first conference. We hope this will be held in Scotland from July 30<sup>th</sup> to August 1st 2010.

If you are concerned with Chromosome 18 disorders, as someone with such a disorder, parent or relative and would like to join this new European organisation please either fill in the registration form on the web site or contact us at [secretary@chromosome18eur.org](mailto:secretary@chromosome18eur.org) and we will send you a registration form.

When you join Chromosome 18 Registry and Research Society ( Europe) you automatically become a full member of Chromosome 18 Registry and Research Society (US). The annual subscription is €30 or £25. If you can afford this please subscribe; if you cannot afford the subscription please join anyway.



**To apply to be a Member** please complete the form below

First Name	<input type="text"/>	Last Name	<input type="text"/>
First Name	<input type="text"/>	Last Name	<input type="text"/>
Institution and Department ( <i>if relevant</i> )	<input type="text"/>		
	<input type="text"/>		
Full	<input type="text"/>		
Postal	<input type="text"/>		
Address	<input type="text"/>		
Country	<input type="text"/>	(Other)	<input type="text"/>
Home Phone	<input type="text"/>	Work Phone	<input type="text"/>
E-mail	<input type="text"/>		
Relationship to Affected Person	<input type="text"/>		

The **Parent Network** is a list of the names, addresses and e-mails of parents who wish to communicate with each other. It is only available to members who join the network.

Please add me (us) to the Parent Network

### **Affected Person**

First Name	<input type="text"/>	Last Name	<input type="text"/>
Syndrome	<input type="text"/>	Date of birth	<input type="text"/>
(Other)	<input type="text"/>		<input type="text"/>

Affected person is deceased

The **List-serves** are internet Yahoo groups that provide an email venue for current Registry members to share issues and concerns of importance to them. Currently, there are four syndrome list-serves:- 18q-, 18p-, Ring 18, and Tetrasomy 18p. In addition there are list-serves for particular groups:- for Relatives and a Spanish-speaking one.

If you would like to join a list-serve, please indicate which one.

We hope to have list-serves in other languages. If this would help you, please state the language you need.

To return this completed form, please press Submit to send it to our web-site or post to: The Treasurer, Chromosome 18 Registry and Research Society (Europe) 1 Chancellery Mews, Bury St Edmunds, Suffolk, IP33 3AB.

**Chromosome 18 Registry and Research Society (Europe)**  
**Registered Scottish Charity: SC040399**

## International Payments

Please pay the membership (of € 30 or £25) by an international bank transfer to our bank account using the IBAN number.

The bank details of Chromosome 18 Registry and Research Society (Europe) are:

**Bank** – HSBC City Corporate Banking Centre

**Account Number** – 72138549

**Sort Code** – 40-05-30

**SWIFT BIC Code** – MIDLGB2141W

**IBAN No** – GB48MIDL40053072138549

**Account Name** – CAF Bank Ltd

**Enter in field 72:**

“For Credit to Chromosome 18 Europe A/C 00018616”

Note: Field 72 is often known as the reference field. For the money to arrive correctly in our account, it should be filled in as shown.

It would help when you have make payment via your bank, if you would send an e-mail to the Treasurer

treasurer@chromosome18eur.org

just saying that you have made a payment (for your security do not give any details, just say that you have made a payment).

## Payments from UK members

You can pay :-

- by cheque payable to the **Chromosome 18 Registry and Research Society (Europe)**
- or
- by BAC transfer.

The *Beneficiary Name* is **Chromo 18 Europe**

The *Sort Code* is **40 52 40**

The *Account Number* is **000 186 16**

## Gift Aid

if you are a UK tax payer and would like us to receive an extra 28% back from Inland Revenue, please fill this form. Using Gift Aid means that for every pound you give to **Chromosome 18 Registry and Research Society (Europe)** gets an extra 28 pence from the Inland Revenue, helping your donation go further. This clearly helps us, and you only have to fill in the form once for it holds until revoked by you.

So, if you want your donation to go further, Gift Aid it. Please complete this form and send it back to the address below.

First Name..... Surname.....  
Address.....  
.....  
.....Postcode.....

I want to Gift Aid all donations I have made to **Chromosome 18 Registry and Research Society (Europe)** since 6 April 2009 and all donations I make in the future, until I notify you otherwise.

Signed..... Date.....

*To qualify for Gift Aid, what you pay in income tax or capital gains tax must at least equal the amount we will claim in the tax year.*

Please return all this form to

**The Treasurer,**  
**Chromosome 18 Registry and Research Society (Europe)**  
**1 Chancellery Mews, Bury St Edmunds, Suffolk, IP33 3AB.**