

# Newsletter



**Special points of interest:**

- Design a poster competition
- Volunteers WANTED
- Have your say—send us your story (see page 3)

## Our r(20) website is now LIVE!

Following your fantastic efforts in supporting our fundraising campaign before Christmas to raise funds to build our new website, you will be delighted to hear that we smashed our fundraising target of £2,000 and raised a huge £2,300!!

Your donations and fundraising ideas/and contributions really have made a difference.

See inside for more details of the most recent funds raised.

I am therefore very proud to announce the launch of our new website:

<http://www.ring20researchsupport.co.uk/>

ring 20 research & support uk Website Fundraising Campaign



yet, but we've created the foundations from which we can expand this valuable resource library.

You can see what we've been up to in **Events**, view the PUBLIC map for known r(20) cases around the world. In **Our Members**, see how you can **Get Involved** with hints and tips on fundraising and all the links you'll ever need for online donations! **Our Blog** is a new feature where you can have your say on anything r(20) - see how Dawn Gray has kindly started this off for us, with our first blog. Currently we have a placeholder page for future **Research** updates—watch this space for news we hope to bring to you during 2015.

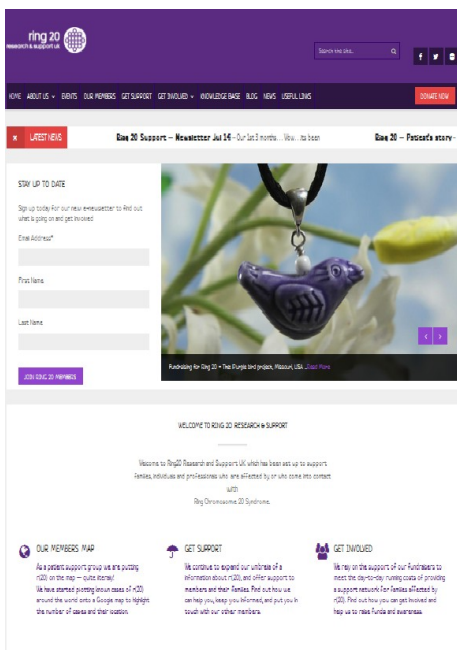
This has been an exciting first big venture for us that you've made possible—so THANK YOU! We hope that the website will be useful not only to you, our existing members/supporters, but also as a valuable resource to any newly diagnosed patients, their families and the professionals that support them (and of course the medical teams that support you too!).

Please take some time to take a look through the new website and let us know what you think—all constructive feedback is welcomed.

Yours  
Allison Watson  
Co-Founder / Secretary

**INSIDE THIS ISSUE:**

Poster competition	2
Volunteers Wanted	2
Fundraising update	3
Grants/Sponsorship	3
Tell us your story	4
Events	4
Research	4
Your Story	5
Patient Support Group Forum	5
Merchandising	5
New email	6
Stay up to date	6



We have worked hard to pull this together, incorporating the latest information on r(20) syndrome in the **Knowledge Base**—our new one-stop shop for all published information on the condition. It's by no means complete

ring 20  
research & support uk



## Design a Poster Competition

Here's your opportunity to get involved:

(address is on the back page of this newsletter).

Over the coming months we hope to be able to attend a number of events and conferences, networking and engaging with professionals in all areas with an interest in r(20) syndrome. We would like to produce a poster and/or cover page for some of our new literature that we are currently pulling together, to share at these events and this is where you come in...

We'd like you to design a poster or picture that illustrates what r(20) syndrome means to you. Our judges will be asked to look for an innovative and eye-catching design that will appeal to the reader and engage their interest in r(20).

Your entry should be on A4 size paper and can include words and/or pictures and must be your own work.

- The winning entry will be drawn in April, so get your entries in to us before the end of March



**Having a spring  
cleanup?  
Sell unwanted items  
and raise funds for us  
on eBay here:**

[http://  
www.ebay.co.uk/egw/  
ebay-for-charity/charity  
-profile/?NP\\_ID=71688](http://www.ebay.co.uk/egw/ebay-for-charity/charity-profile/?NP_ID=71688)

**Don't forget to sign-up  
to *easyfundraising* and  
earn funds for us on  
your online shopping!**

**Join here:**  
[http://  
www.easyfundraising.org  
.uk/causes/  
ring20researchsupport](http://www.easyfundraising.org.uk/causes/ring20researchsupport)

## Volunteers wanted

Running even a small charity like **Ring20 Research and Support UK** takes a huge amount of time and resource—and we are all volunteers with day jobs and families, just like you. In order to achieve more of our aims for this year, we really need more 'hands, minds and time'. Can you offer to volunteer for us in any way? If so, do get in touch...

We are looking for help in a number of areas including:

- Social Media updates—are you a dab hand at Facebook/Twitter? To keep our website up in the top Google listings for r(20) we need to keep active in this space...and keep our ears to the ground for any interesting articles to share with the group
- Events— can you spare a few hours to help setup and/or co-host a stand at a conference and/or talk to others about your experiences of r(20) to help raise awareness?

- Fundraising—we really need lots of ongoing help with fundraising events, ideas and promotion.
- Raising Awareness of r(20) - there are lots of groups with whom we wish to engage to raise awareness
- Other? - there's lots of other things you could do, even if you only have a few hours to spare and/or access to a telephone or email.

**Let us know if you can help!**



**easyfundraising**  
.org.uk

## Fundraising update

We hope you enjoyed receiving our regular weekly campaign emails and seeing us creeping towards our target?

The latest fundraisers that haven't yet made it to our website:

### Raffle and Non-uniform day

Katy Brennan held a Christmas Hamper raffle and non-uniform day at the school where she works and raised a superb **£165**. Well done to all the staff and pupils at Castle Hill High School, Stockport who supported us.

### Havering Revenues Christmas Club

A friend who works for Havering Revenues kindly arranged for them to donate the interest from their Christmas club savings for 2014 to us. A big thank you goes out to them for our **£250** donation.

Even though our website campaign is over, we still need to keep fundraising to maintain the ongoing running and activities of the charity, especially if we want to achieve more in the future e.g. raise money to get involved in research. We appreciate any help or ideas that you have for **Fundraising**. See our fundraising page for more information or get in touch:

<http://www.ring20researchsupport.co.uk/get-involved/fundraising/>



### Upcoming events

#### Half Marathon

Allison has successfully gained a place in the Royal Parks Half Marathon, London in Sept '15. She will be running for **Ring20 Research and Support UK** and will be looking for sponsorship, later this year...

#### Race Night

We are considering hosting a race night including dinner in the summer. If you'd be interested in joining us, please let us know. If we can gauge sufficient interest we will look to make this happen.



<https://www.facebook.com/Ring20ResearchandSupportUK>

Please  our **Facebook page to keep up-to-date on all that's happening!**

## Grants and Sponsorship

### Corporate Sponsorship

We have received a cheque for £200 from IFDS to help us with our vital work.

### Matched giving

We have been successful in securing matched funding via Dave Watson, through his workplace National Grid (Gas) for our Indian Buffet Night at Rajmoni last August. We have just received a cheque for **£375**—which is fantastic.

**Does your workplace offer any corporate sponsorship for charities such as ours?**

### BIG Lottery—Awards for All

You may have seen our recent request for your views on Raising Awareness? Don has used your input to complete our first BIG Lottery 'Awards for All' Grant application for funding for a project to raise awareness of r(20) syndrome through engagement of medical professionals at targeted conferences. Our aim is to attend at least 2 large conferences over the next 12 months, with a primary audience of neurologists and geneticists, to highlight the need for correct diagnosis and treatment options.

Chris is also helping us to put together some smaller grant funding applications too.

ring 20  
research & support uk





## Events

### Findacure workshop

Allison attended a workshop at the end of January entitled 'How to identify rare disease patients'. Whilst some of the content was aimed at finding patients for clinical trials, the ideas were just as useful in terms of recruiting patients for support groups like ours. We may look to put some of the ideas into practice, as we would like to grow so that we can help more families in need.

As it is Rare Disease Day at the end of this February (and r(20) is in the ultra, ultra rare category of diseases!) we are focussing our attentions on raising awareness and networking in this area at the following events:

### Royal Society of Medicine—The unusual suspects: A symposium of rare diseases

On 25th February Don and Allison will be attending this event on behalf of r(20) patients..



about rare diseases that they would not necessarily become familiar with at medical school.

This meeting aims to encourage medical students and trainees to develop understanding and awareness of rare conditions to reduce time to diagnoses. At the end of the meeting, medical students and trainees will be informed

### 1<sup>st</sup> UK Genetic Disorders Leadership Symposium

On 6/7th March, Allison will be representing Ring20 Research and Support UK at this inaugural event.

The goal is to bring together leaders of UK based genetic disorder charities and other patient advocates to create an environment in which they can learn from experts, share best practices and network. It is of critical importance to help those advocates affected by genetic disorders 'stakeholders in their own care', and this Annual Symposium is set to address these and other important topics in a first of its kind collaborative event.



There are a number of other opportunities open to us and we would have also loved to have represented r(20) families at the following, but due to resource constraints we have had to bypass these this year:

- House of Commons (English Parliament) Rare Disease Day Reception
- Royal Holloway (University of London) - exhibition, lectures, hands-on workshops and other activities will showcase rare disease research and care, and introduce attendees to freely available resources related to rare disease.



**The Rare Disease Day 2015 theme Living with a Rare Disease pays tribute to the millions and millions of parents, siblings, grandparents, spouses, aunts, uncles, cousins, and friends whose daily lives are impacted and who are living day-by-day, hand-in-hand with rare disease patients.**

## Research

We have been approached by a paediatric neurologist in the UK with an interest in r(20), who would potentially like to complete a clinical study. Some work has been undertaken in this area previously, however this would be the largest study on r(20) of its kind for UK/European patients.

Discussions are in the early stages and there may potentially be a requirement for funding to facilitate this study—which as a group we may be asked to help with...?

If this goes ahead, we would give members the opportunity to register their interest in being a participant in the study, which we know a number of you have previously expressed an interest in.

Our Medical Advisor, Sophie is looking into the possibility of arranging an audit of r(20) patients around the UK and Ireland, through the BPNSU. The concept is subject to approval, but

we are hoping that this will get the go-ahead in the next 6 months.

Prof Canevini's team in Italy continue their research into r(20) and are currently looking for funding for their latest project—though we expect this to be sizeable and outside of our remit to assist with funding at this stage.

As our name suggests we are keen to get involved and promote research projects that might be to the benefit of r(20) patients. Funding requirements in this area can be considerable and cannot be undertaken lightly. However, we remain optimistic that we can endeavour to fundraise for such engagement. **Our next fundraising campaign? If this is important to you, please tell us...**

We will obviously keep you posted on developments on all of the above...

## Tell us your story

As mentioned on the front page, we have a new **Blog** page on our website.

This is an area where we hope anyone with an interest can share their thoughts/views/experiences with others visiting the site.

We would also like to start to collate some personal stories to share to support future funding applications and at events, to raise awareness of what living with r(20) is really like.



Do you have a story to tell? Or have something that you want to air? If so, send us some words (and pictures) and we'll post them up for you!

## Patient Support Group Forum

Do you currently use our Facebook CLOSED support group?

We are aware that some of you are not comfortable with using Facebook as a communications tool, for a variety of reasons.

There are alternative forums available for support groups like ours and we will be looking into these as alternative, or indeed *additional* options for the future.

Some forums even accommodate translation into 5 languages— so could be a great help for some of our overseas members!

## Merchandising

Our lovely polo-shirts and hoodies are still available to order from WERX. See our **Merchandising** page on our new website for how to order yours:

<http://www.ring20researchsupport.co.uk/get-involved/merchandise/>



We still have a few 2015 calendars remaining—again see website for how to get yours!



## About Rare Diseases

**In Europe, a rare disease is defined as one with an incidence of less than 1 in 2,000 people. While each of them is rare, there are more than 7,000 rare diseases, which together affect 24 million (six per cent) people in Europe and take 20 per cent of all health care costs. Improving the care and developing diagnostics and treatments for people with rare diseases are now international priorities.**

ring 20  
research & support uk



## NEW! Email address

With the launch of our new website we have a new general email address so that you can contact us more easily:

Please use this new email address going forward.

[ring20@ring20researchsupport.co.uk](mailto:ring20@ring20researchsupport.co.uk)

## Stay Up To Date

Around our website you'll notice the opportunity to STAY UP TO DATE. Here you can provide us with your latest contact details, so we can ensure we stay in touch with you and can provide you with any breaking news, as it happens.

Going forward we hope that the website will become our main platform for communication to all our members/supporters, but from time to time we may wish to contact you one-to-one.

So make sure you complete your membership sign-up TODAY!

### Ring20 Research and Support UK

26 Headley Chase  
Warley, Brentwood  
Essex CM14 5BN  
England

Phone: 00 44 1708 403620  
E-mail: [ring20@ring20researchsupport.co.uk](mailto:ring20@ring20researchsupport.co.uk)

We hope you have enjoyed reading our latest newsletter.

If you wish to receive future editions (we are anticipating producing these periodically, approx. 6 monthly), please ensure you sign up to our mailing list on our website here:

<http://www.ring20researchsupport.co.uk/>

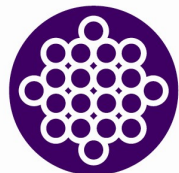
Any feedback on content and what you'd like included in future editions, please contact us to let us know. And of course, we would welcome any contributions of your own for inclusion.

Find us on the web:

<http://www.ring20researchsupport.co.uk/>

*Supporting families, individuals  
and professionals affected by  
or who come into contact with  
Ring Chromosome 20 Syndrome*

**ring 20**  
research & support uk



Any medical information included herein is merely to signpost readers to information that is freely available. Ring20 Research and Support UK do not provide medical advice and patients seeking such, should always consult with their own medical team.