

Welcome to our first newsletter of 2020. We have decided to try and get this going again in these uncertain times to let you know of work going on in the background, information that may come in useful and to encourage our members to get involved and share their experiences. We are a small team, so please send on any news, tips, insights and suggestions to our secretary or editor. Grab a cuppa and enjoy the read.



NIC 105731

RCN 20204769

INTRODUCING OUR BOARD

As most of you know, as off October 2019, we are now legally recognised as a charity both in NI and ROI, we have two different registration numbers, but we will operate as one organisation. We have 10 board members, so we will introduce these to you one by one in these newsletters.

First up is our Chairperson Patricia Ryan.



Patricia lives in Galway and has been involved with Vasculitis Ireland Awareness for more than 5 years.

She is interested in all aspects of the Charity and volunteers her time and support as she can, to help the organisation in its many activities. She is the current Chairperson for the organisation, agreeing to take over for a second period, after Andrew McCann resigned last year. Her background has been in nursing and research and she uses this knowledge to contribute to the strong collaborations that VIA has embedded with the many national and European networks.

The photo opposite is from VIA collaboration with Vifor and is taken from the recent publication of Rare Revolution magazine which especially featured Vasculitis in the month of May.

<https://edition.pagesuite.com/html5/reader/production/default.aspx?pubname=&edid=f511f3d7-ee38-41d7-b6d9-243e4de20f28>



BACKGROUND WORK

Nuts and Bolts

We now have all our policies updated and Tim will soon be able to get them on the website. The board will be meeting in the coming weeks to carry out a 'Healthcheck' on our governance so you can be assured that we are fully compliant with GDPR, and both Charity Regulatory bodies. Our accounts have been audited and we will shortly be sending our end of year report and audited accounts to both Charity Regulators. Our insurance has just been updated to include the whole island of Ireland and we are delighted that this has been possible to achieve with a single policy.

Raising Awareness and Involvement in Policy Change



<https://www.ipposi.ie>

<https://www.nirdp.org.uk/>

Through IPPOSI, we are signatories on the newly developed Charter for Patient Involvement in Medicines Assessment and Reimbursement in Ireland https://www.ipposi.ie/wp-content/uploads/2019/02/IPPOSI_Patient-Charter_A4_LO_FINAL.pdf and have been actively involved in empowering the patient voice.

We continue to work closely with the NIRDP and were instrumental in delivering the Joint North South Rare Disease Day this year.



We will tell you about our involvement with these and other organisations in coming newsletters

We had our first ever World Vasculitis Awareness Day on 15th May 2020.

We had patients, carers, scientists, clinicians, researchers from all over the world take part, even the Chile Vasculitis group Chair got involved. We got over 7 thousand views so well done everyone. See the result [here](#). A huge thank you to all who helped in making this possible.

John Mills (Patient, Vasculitis UK),
Peter Verhoeven (Carer, Vasculitis Stritching, Netherlands),
Nikki Preece (Patient Member),
Cecil Armstrong (patient member),
Elisabeth Verhoeven (Patient, Netherlands),
Susan Mills (Carer, Vasculitis UK),
Maurice O'Leary (Patient member),
Shirley Quinn (Patient member),
Vicki (RKD Nurse),
Samantha Dunne (our Facebook guru, Patient member),
Lynn Campbell (Carer),
Campbell family,
Maria Christofou (Early stage researcher HELICAL Project),
Prof Mark Little (needs no introduction!),
Aisling Murphy (Research Nurse),
Jennifer Scott (Nephrology Specialist Registrar),
Patricia Ryan (Chair VIA),
Eddie Lyons (Patient member),
Andrew McCann (Former Chair VIA),
Caroline Speers McCann (Carer and fundraiser extraordinaire),
Tim Whymark (VIA Board member and website manager, Patient Member),
Doris Ximena Romo Quintana (Chile Vasculitis support group)
Cathy Neilis (VIA Board member, Patient member)
Charlie Power (who put all the clips together)

Latest Research

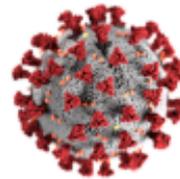
Research into COVID-19 in Vasculitis

DeCOMPRESS

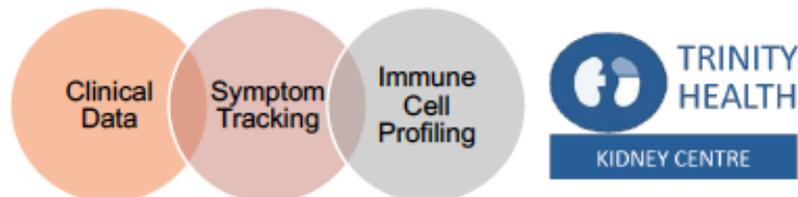
Researchers at Trinity College are studying the effects of immunosuppressive medications on COVID-19

If you, or someone close to you:

- has tested positive for COVID-19; OR
- has received a test for COVID-19;



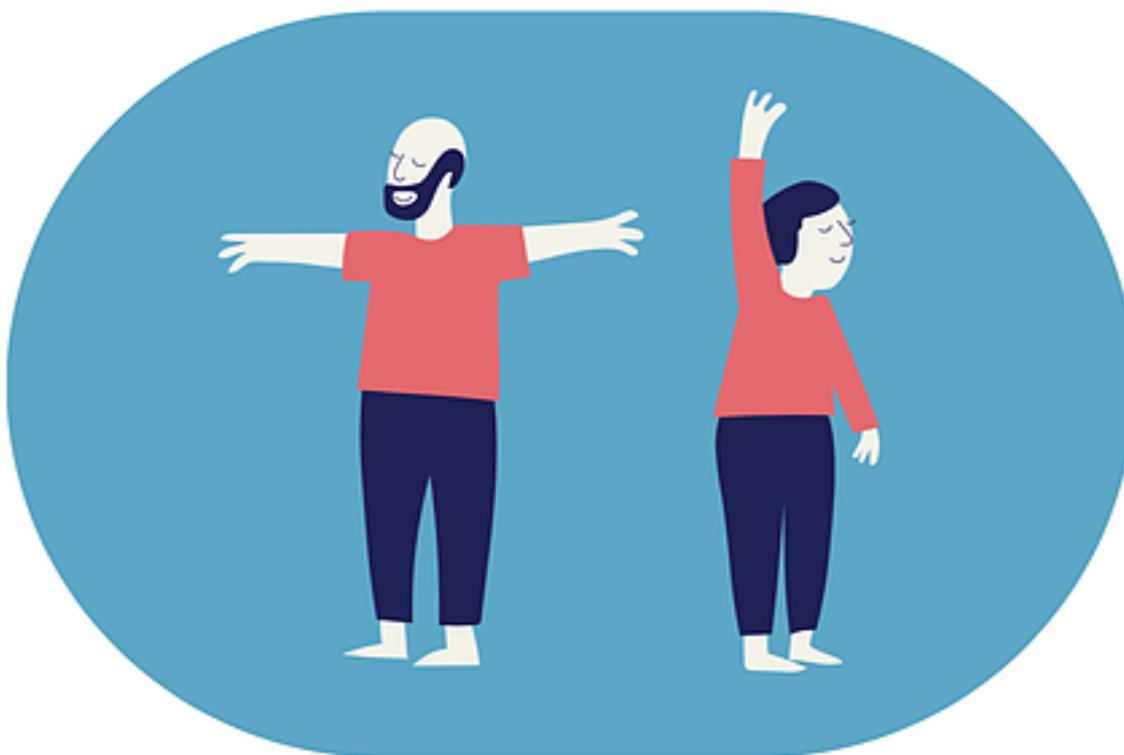
1. Please visit the DeCOMPRESS study [webpage](#)
2. Please contact Vicki rkd nurse@tcd.ie for info about how you can get involved



[Click here to watch a short video of Prof. Mark Little explaining the research study](#)

Please print this flyer out and give to your GP/ Clinics to help raise awareness of this study

The Recommended Site – spotted by members, used by members and has positive feedback



ExWell @ Home is a sophisticated home exercise programme developed by our expert team, for people with all types of chronic illnesses.

What will the programme entail?

- You will receive a guide to self-assess your fitness at home, this will give the team an accurate view of your current abilities.
- You will then receive a personalised exercise plan with a booklet and diary to log your activity.
- There will be online videos to help guide you as well as live stream classes to follow along to.
- You will also receive an activity tracker to record you step counts.
- Each week, a member of staff will call you to answer any questions you might have and help set attainable goals with you to keep you motivated.

<https://www.Exwell.ie/>



Don't forget our next Zoom meeting on 8th July 11am to 12.30, join us for a cuppa and a chat

Meeting ID: 810 2748 3661

Password: 455332

Check our website and Facebook page for any updates

To help us support you in these peculiar times, we would be grateful if you could complete this short survey. It will take 2 minutes to complete.

<https://www.surveymonkey.co.uk/r/RZLX93P>

We hope you enjoyed reading this update and we look forward to bringing you more. Please let us know of anything you want included, any good tips/advice/books/sites/classes you come across.

Keep Well and Keep in Touch,
The Editor (Julie this time!)