



Welcome to our new-look newsletter!



As always, there's so much to report on this summer, and never enough room to fit it all in! We've been incredibly busy here at Societi HQ - and many of you have been just as busy, with so much fundraising and awareness raising happening. It's been a brilliant first half of 2023, for tiny hearts! We've seen amazing progress with our Children's Hospital Partnership Programme, phenomenal success at the RCPCH conference (see below!), the release of fabulous new family films, an RCPCH endorsed clinician training film, press coverage seen by 25 million people... and the list goes on!

And there's so much to look forward to, too - with additions to our Societi team, our aspirations to reach the RCGP conference this October, our preparations for World Heart Day 2023 and all the brilliant fundraisers that are planned. We're so fortunate at Societi to have so many dedicated and passionate supporters. What you do, every pound you raise or donate, and every bit of awareness you raise is the KEY to our work!

A HUGE THANK YOU from me, to everyone who has donated, fundraised, run marathons, volunteered, shared posts, climbed peaks, baked cakes, raised awareness and more. We need your continued support, ideas and energy and I hope, as we head into the second half of the year, you'll be right there with us...there's thousands of children's hearts counting on it! Together we ARE getting Kawasaki Disease known and we WILL protect tiny hearts!

Rachael, Societi Founder



Societi sees HUGE success at the 2023 RCPCH conference!



As part of our Children's Hospital Partnership Programme, generously funded by the Randal

Charitable Foundation, Societi once again had the amazing opportunity to exhibit at the Royal College of Paediatrics and Child Health (RCPCH) annual conference.

Our stand looked FABULOUS!!!! So many of YOU generously gave us your wonderful pictures to use - all unidentifiable of course! YOUR photos gave the paediatricians visiting our stand a real sense of the children in our community, the scale and impact that Kawasaki Disease has on our children and helped them to understand just how important we believe it is for them to KNOW Kawasaki Disease - THANK YOU!

We're delighted to report that the interest in Kawasaki Disease shown at the conference was remarkable. SO MANY powerful and diverse conversations with those that care for our children....medical students, paediatricians, nurse practitioners, and GPs all showed a keen interest, like never before, in our work.



Our stand was constantly busy and we were inundated with doctors wanting to know all the latest about Kawasaki Disease, hungry to take away our clinical information and learning resources.

It's YOUR support, donations, fundraising and your regular contributions that made all of this possible! THANK YOU for making this a very special conference indeed, and one

where we have absolutely, tangibly and definitely protected tiny hearts.

HUGE THANKS too, to the incredibly supportive Randal Charitable Foundation - providing funding so we could be there - and for funding so many of the training resources that were so eagerly consumed!



What have we
been up to?

What have YOU
been up to?

Get involved!

**Donate
here!**

**What have we
been up to?**

**What have YOU
been up to?**

Get involved!

A warm WELCOME to the fabulous people joining #TeamSocieti!

Societi has always been fortunate to be supported by outstanding people and our two additions to the Societi team are no exception. We're delighted to be able to welcome Trustee, Professor Mike Danson and Communications & Events Lead, Ria Wicks.



Prof Mike Danson - Trustee

Professor Mike Danson is no stranger to Societi; he's generously supported our organisation in many ways from our very start. A recognised, UK-leading statistician, economist, and Professor Emeritus of Enterprise

Policy, we're so fortunate and delighted to have Prof Mike's expertise and enthusiasm within our Board of Trustees. Welcome Mike!



Ria - Communications & Events Lead

We were excited to welcome Ria into the staff team earlier this year, as our Communications & Events Lead. Ria's experience as a Senior Communications Officer, alongside working with senior leadership teams as an executive assistant means she's got many fabulous and versatile skills that are already underpinning and driving our work.

Welcome Ria!



STOP PRESS **STOP PRESS** **STOP PRESS**

Mike and Ria aren't the only recent additions to #TeamSocieti!! We are so pleased to announce that our very own Rachel Jarvis, whom many of you will have had contact with, gave birth to Cyril 'Dak' Jarvis on 12 August weighing 10lbs 11oz!! We just can't wait to meet baby Dak and welcome him into #TeamSocieti! Of course, Rachel will be taking a well deserved 'baby break' from her Societi duties but will be back replying to your emails in no time! Huge congratulations to Rachel, Ben and all their family and friends!



What have we been up to?

Our work to raise awareness of Kawasaki Disease, improve clinical supervision, enable research and support families continues with pace and as ever, we've been busy! Thank you to everyone, every family and organisation for all you do - without you, the projects and activities packed into this newsletter wouldn't be possible. THANK YOU for EVERYTHING you do! *Claire, Strategy, Design & Research Lead*

New for 2023: FABULOUS family films



We're so grateful to Laura, Alister, Manda and Olivia

Four very special families generously gave their time and shared their stories so we could make four new family films.

Laura, Alister, Manda and Olivia were brave enough to share their Kawasaki Disease experiences on camera, to help other families affected by Kawasaki Disease. Working with the amazing Animation Guys, a total of five family films were produced, including one with snippets from each story, and released on International Kawasaki Disease Awareness Day. In creating these films, we're both raising awareness of Kawasaki Disease and helping families facing Kawasaki Disease to make a 'virtual' connection with families who have been through their own, unique, Kawasaki Disease journey. If you'd like to watch our Family Films you can do so on our YouTube channel [here](#). And a HUGE thank you to Laura, Alister, Manda and Olivia - **you're all Societi superstars.**

UPDATE: KD-CAAP research trial

The KD-CAAP trial, researching acute treatments for Kawasaki Disease is continuing across Europe.

The trial which now has 42 open centres across 10 European countries has now recruited its 64th patient which is just fabulous progress.

We continue to support the trial, attend meetings, and have provided materials about Societi and the trial for the General Assembly to be distributed to national hubs across Europe. And of course, we continue to update and make information available to patients,

their families, clinicians and other interested parties on our [website](#) and on Twitter.

We have also been asked if we can translate the information on our trial materials into other European languages to make them even more useful to participating centres. This is something which we are looking into and so if you feel this is something you would be able to help with, please do [get in touch](#).



UPDATE!! Children's Hospital Partnership Programme – Year 2!



We're in the second year of our 3-year Children's Hospital Partnership Programme. Made possible by funding generously invested by the Randal Charitable Foundation, the programme aims to improve and save the lives of children affected by Kawasaki Disease in the UK, by ensuring more doctors know Kawasaki Disease. Here's just a snapshot of some of the work we've already been able to complete:

Producing our new Kawasaki Disease training film



We've created a phenomenal, and RCPCH Education and Learning Committee ENDORSED training film for doctors! It's a really powerful resource in our

campaign to get Kawasaki Disease known. It's now been shared hundreds of times and links sent to each of our programme teams too. A huge THANK YOU to incredible Societi doctors – Dr Jethro Herberg and Dr Harsita Patel, for all the work they put into this important project, generously donating their time too. Societi is fortunate to be supported by the phenomenal expertise of many fabulous doctors, ensuring clinical accuracy and making sure our top quality resources can be trusted by healthcare professionals and families too.

Reviewing, updating and creating new resources

We've produced a range of training and learning tools to help paediatricians understand, diagnose, treat and manage Kawasaki Disease.

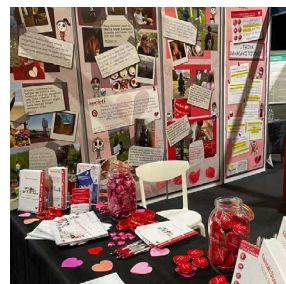
Our resources are regularly reviewed and updates issued. Our newest resource, our 'Little Book of Kawasaki Disease' is packed with information: things we think (hope!) doctors will already know about Kawasaki Disease and a host of things that perhaps they won't (yet!). We want all doctors to know Kawasaki Disease so that children affected get the urgent care they need.



Kawasaki Disease symposium

Working with colleagues at Great Ormond Street Hospital, a children's heart health and Kawasaki Disease learning event took place in May, with over **150 doctors attending**.

Huge thanks to Societi Scientific Advisory Board member, the amazing Dr Filip Kucera, who orchestrated the paediatric cardiology event. With funding generously donated from the Randal Charitable Foundation, Societi was able to provide clinical training resources, and information about Societi's work for every attendee, sharing knowledge about a range of aspects of Kawasaki Disease.



RCPCH conference

Societi has committed to attending the Royal College of Paediatrics and Child Health (RCPCH) conference each year throughout the programme. You'll see on the previous page, the spectacular impact you helped us make this year, directly engaging with at least

400 paediatricians and healthcare professionals. With intense interest in Kawasaki Disease and our work, a huge number of attendees took away piles (and piles!) of Kawasaki Disease information and clinical learning resources, taking materials back to **hundreds of hospitals – worldwide!**

Recruiting more hospitals to our partnership



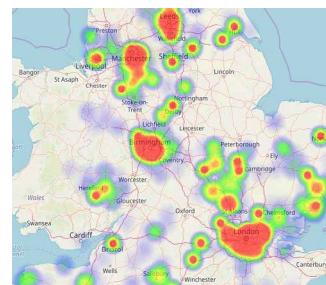
We've now recruited a massive **73 doctors** across **39 brilliant hospitals!** Recruitment is an ongoing task and we are always looking to expand our network of hospitals. We've been able to recruit hospitals by meeting doctors at events

and through YOUR nominations of YOUR local hospitals. A donation of £30 helps if you'd like to nominate your local hospital – it goes towards materials development and postage costs – just [get in touch](#) to find out more.



Measuring our impact

We know we need to understand the impact of our work – so we've been busy gathering data on hospital admissions for Kawasaki Disease over time, across Northern Ireland, Scotland and Wales and partnering with NHS England too. The database we've developed will help us report against programme impact – we'll have probably the best understanding (ever!) of how many children are being affected by Kawasaki Disease in the UK, as well as where they live. Our Diagnosis Day study which so many of you helped us with, also provides qualitative information to inform programme benefits and outcomes too.



Donate
here!

What have we
been up to?

What have YOU
been up to?

Get involved!

Working with NHSBT to reach 25 million people!

We were delighted to partner with NHS Blood and Transplant (NHSBT) for our BIG day, Kawasaki Disease Awareness Day, this year. Together with the communications team at NHSBT, a media release was prepared to highlight the importance of plasma donations – and the need for more donors. IVIG, made from plasma, is a key treatment for Kawasaki Disease, in fact Kawasaki Disease is in the top ten diseases which IVIG is used to treat in the UK. The press release was picked up by the Express, Sky News, ITV, the Independent, the Sun and many more national news outlets. We were inundated with your feedback – telling us how exciting it is to have Kawasaki Disease discussed in headline news. The combined readership of outlets reached exceeds 25 million people -- just incredible! If you'd like to find out more about what we got up to on Kawasaki Disease Awareness Day 2023, you can read our impact statement [here](#)!



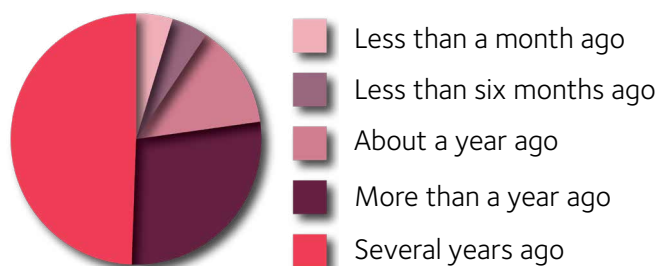
Your LAST CHANCE to complete the Societi Supporter Survey!

Earlier this year, we conducted a supporter survey to find out exactly what YOU think about Societi and our work. Thank you to EVERYONE who replied – we were absolutely thrilled at the number of replies we had to the survey and just delighted by some of the things you had to say. The results give us an amazing insight into the things we are doing well, the things we could improve and the things you would like us to do in the future. We are so fortunate to have YOUR support meaning we can do so

much more, much quicker to improve the outcomes for children affected by Kawasaki Disease and protect tiny hearts – THANK YOU!

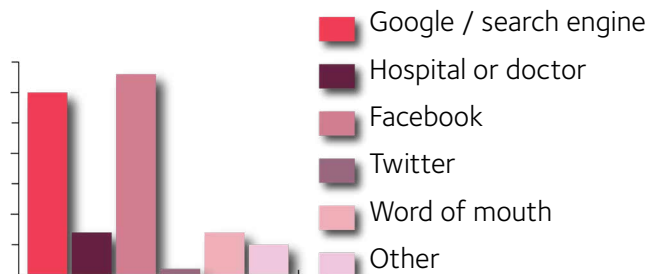
We'll be ready to report the survey results to our Trustees very soon, but as we've had so many new followers recently, we wanted to open the survey up again. So, this is your **LAST CHANCE** to complete our short survey! You can access the survey [here](#). Below is a sneak peek at some findings from the survey so far:

How long ago was it when you found out about us / first visited our website or our Facebook page?



One fabulous outcome of the survey revealed that a MASSIVE 78% of respondents have supported Societi for over a year and a HUGE 50% for several years. We are just delighted to know that our supporters choose to continue to follow our work and support us long after their families have been affected by Kawasaki Disease.

How did you hear about Societi Foundation?



Our survey results, indicated that families affected by Kawasaki Disease tend to find out about Societi through Facebook or by searching the internet. Only 8.5% of families found out about Societi through their hospital or doctor – this is something we are working to change, especially through our Children's Hospital Partnership Programme.

If you've visited our family portal, please give us some feedback so we can continue to improve it? Was it helpful? What else could we add that you'd find useful? The below word cloud is based on the responses to this question in the survey. The bigger the word or phrase, the more times it has been mentioned.

member of every family info all in one place Easy to navigate
Google search family stories helpful tool tool for families expert doctors
Found it really useful helpful useful new families
testimonies helpful Easy stories are helpful Kawasaki similar stories
Factual families experiences trusted information stories and support

Donate
here!

What have we
been up to?

What have YOU
been up to?

Get involved!

**Donate
here!**

**What have we
been up to?**

**What have YOU
been up to?**

Get involved!



What have YOU been up to?

As Chairman and Trustee of Societi Foundation with a lifelong clinical interest in Kawasaki Disease, the work our organisation does is extremely close to my heart! My gratitude to each and every person who has given their time, shown passion and worked hard, helping us to achieve our organisational aims and get Kawasaki Disease known! Thank you for all that you do! *Professor Rob Tulloh, Trustee and Chairman*

THANK YOU to our regular donors!

Our ultra-generous supporters who make a regular monthly donation to Societi enable us to plan ahead for our work, raise awareness and commit to long-term projects. We appreciate YOUR commitment to our cause – more than you could know. Each one of these INCREDIBLE supporters powers our work everyday, and our promise to you, in return, is to keep getting Kawasaki Disease known! THANK YOU! Making a regular donation is easy, please just visit our [JustGiving page](#) to find out how.



Celebrating #TeamSocieti – and YOUR amazing achievements!

The below is just a snapshot of some of the many fabulous, dedicated people who have supported Societi recently. Thank you to absolutely everyone who has donated, raised funds and raised awareness of Kawasaki Disease. We are hugely grateful!



Rosie's heart hike

Courageous Rosie completed the Yorkshire 3 Peaks Challenge in May – 24.5 miles and 1,500m of ascent (which is very nearly a marathon distance whilst climbing higher than Ben Nevis!) She did it in 11:40hrs! Astounding! Rosie raised a staggering £2,375 – funds that will go such a long way to helping us in our work. What makes Rosie so special is that in January 2022 Rosie needed life-saving open heart surgery due to catastrophic damage to coronary arteries caused by Kawasaki Disease. Her journey with Kawasaki Disease is a long and scary one, but thankfully Rosie is now getting back to full heart health. THANK YOU Rosie!

A skydive to raise Kawasaki Disease awareness!

Thank you to fabulous Jonny, Jim and Martin who held their nerve, took to the skies and jumped from a plane with just a parachute! WOW! What a terrific achievement. Not only this, but they also raised a PHENOMENAL £1,945.00 for Societi! Thank you to friends, family and colleagues who donated so generously. HUGE THANKS to Jonny and Sarah who are such an inspiration to us – their fundraising and awareness raising will have a positive impact on other families' experiences with Kawasaki Disease in future.



Fundraising powerhouse – Peter's 80th birthday celebrations raise nearly £1,000

Long standing supporter Marie and her fabulous friends and family – also known as 'Team Thomas', carried on in their unwavering support for Societi Foundation in July when Marie's wonderful dad Peter decided to dedicate his 80th birthday celebrations to raising funds and awareness of Kawasaki Disease. We'd like to say a Happy Birthday again to Peter – and a HUGE thank you. Peter has done so much over many years now, together with Marie and all their family and friends. This time they raised almost £1,200 – phenomenal!!!

A marvellous marathon for Michael!

Michael ran the Leeds marathon for Societi in May this year, raising over £1,800! Astonishing! We're incredibly grateful to Michael and his generous friends and family that have donated and sponsored him. Michael also did a radio interview which was aired on Heart, Smooth and Capital radio stations in Lancashire. The listening numbers are HUGE for such popular and well-known stations, and he'll have reached a whole new audience – informing them about Kawasaki Disease – just INCREDIBLE!



Ben smashes the Rutland Spring Half Marathon!

Ben took on the Rutland Spring Half Marathon in April and his family and friends were there too showing their amazing support! Ben wanted to finish his first half marathon in 2 hours and he did it in.... 2 hours!!! AMAZING! In a field of 500+ runners, Ben had the most distinctive red running top ... it really did stand out. And it reminded us that we really do rely on our wonderful supporters taking on these challenges, to get Kawasaki Disease known. Thank you Ben for all you have done to protect tiny hearts!



Here's what's happening soon!

As Societi's new Communications and Events Lead, I can't tell you just how excited I am to be able to work with all our amazing supporters who are so busy training, planning and working hard to get Kawasaki Disease known. I have been so inspired in fact, that I've decided to take part in an event myself....find out more below! I'm sure you'll be inspired too, by the sheer determination of so many fabulous people. The following pages are dedicated to what's coming up – and there's plenty to get involved in. Just **get in touch** and we'll be here to support you in whatever you decide to do! *Ria, Communications and Events Lead*

Donate
here!

What have we
been up to?

What have YOU
been up to?

AMAZING supporters plan to GET KAWASAKI DISEASE KNOWN!

Kevin continues climbing for Kawasaki Disease awareness!

You may recall phenomenal Societi supporter Kevin, who is currently completing the 214 Wainwright Challenge for Kawasaki Disease awareness. We're so excited to let you know that Kevin is now more than half way through his mammoth challenge having completed a mega 112 Wainwrights!!! Astounding!!! Kevin has plans to continue with his challenge very soon so, if you'd like to support him and help to keep him climbing for Kawasaki Disease awareness you can do so [here](#).



Societi-Sounds! Jack's charity music night

Super-Societi-supporter Jack has been busy arranging a charity music night to raise funds and awareness of Kawasaki Disease – what a FABULOUS idea! The music night on 27 September will feature improvised sounds with electronica and jazz with Steve Davis (yes, the snooker player!), Gaz Williams, and John Biddulph – at the Servant Jazz Quarters, in London. If you fancy an evening filled with some great music while supporting Societi at the same time, then grab your tickets [here](#)!

Andrew to take on the London Marathon 2024!

We're just delighted to share that the wonderful Andrew will be running the 2024 London Marathon for Societi!! Andrew's son was diagnosed with Kawasaki Disease – luckily, his symptoms were spotted early, resulting in a quick diagnosis and urgent treatment. This has fuelled Andrew's passion for raising awareness of Kawasaki Disease. If you'd like to support Andrew's London Marathon you can do so [here](#). All donations count (no matter the size!)



El's London Landmarks Half Marathon

Another member of 'Team Thomas', and another amazing fundraiser! The wonderful El got in touch recently to let us know that she will be running the London Landmarks Half Marathon in April 2024. We're so grateful to El who continues to support Societi and has already done so much to raise awareness of Kawasaki Disease. If you'd like to support El's London Landmarks Half Marathon and help her as she runs to protect even more tiny hearts, you can sponsor her [here](#).

Making a splash about Kawasaki Disease!

You might remember that last year, fabulous Samantha was all set to take part in the Swim Serpentine which unfortunately was cancelled last minute. The place rolled over to this year and we are just delighted to let you know that our very own Ria has decided to take on the mantle to raise awareness of Kawasaki Disease while swimming a half-mile distance in the Swim Serpentine event this September. If you'd like to support Ria in her fantastic challenge, you can do so [here](#). There's nothing like getting dropped in the deep end! Good luck Ria!



Inspired? What could YOU do?

Raising awareness of Kawasaki Disease is Societi's #1 priority – it's the most effective way we have to protect tiny hearts. We aim to reach EVERYONE in the UK – that's 66 million people! WE NEED YOUR HELP!

There are so many things you can do to raise funds and awareness of Kawasaki Disease! Run a marathon – not a runner? Hold a cake sale – not a baker? Hold a coffee morning! Or why not display some posters around your local community! Whatever you decide to do, we'll be there to help. Visit [our website](#) for more ideas and [get in touch](#) – we'll always try to help where we can!



Could YOU help to shine a light on Kawasaki Disease?



We're excitedly anticipating World Heart Day in September but that doesn't stop us being busy planning for International Kawasaki Disease Awareness Day too! Thanks to our fabulous supporters, more landmarks across the UK than ever before lit up on 26 January this year for Kawasaki Disease awareness, and we need your help to make an even bigger impact next year.

Can you speak to your council or landmark owner to ask them to light up your local town hall, cathedral or a landmark to get THOUSANDS of people in your area talking about Kawasaki Disease? [Get in touch](#) – let us know who you have contacted and we'll send them our press release too!

Get involved!

Protect tiny hearts on 29 September – World Heart Day!



WORLD HEART DAY 29 SEP

We can't wait for 29 September – WORLD HEART DAY!! This is simply a MASSIVE day in our Societi Foundation calendar! There's so many exciting things going on in preparation for World Heart Day at Societi this year, including the creation of a new Family Story podcast series, a Kawasaki Disease into adulthood podcast series, the Societi Virtual



10K, our RCGP fundraising campaign, working with the World Heart Federation to raise awareness of children's heart health... and so much more! There's so much to get involved with, so come on and help us protect tiny hearts this World Heart Day!

Help us reach our target and get to RCGP!



Following the Societi survey, shared with all our supporters earlier this year (a big THANK YOU again to all who completed this), your feedback highlighted your desire for us to get even more GPs to know Kawasaki Disease. After reading many comments regarding a lack of support or information available from GPs too, as well as specific requests for Societi to attend the annual Royal College of GP's (RCGP) conference, we decided it's time to act! So... we're hoping to attend the RCGP conference, this October!

BUT – WE NEED YOUR HELP! Attendance at conference costs a LOT.... But we're determined! So we're already well underway with our plans for the conference!

Can YOU help us fill the funding shortfall we have? We hope so! Help us reach an audience of over 1,000 GP's... Imagine the difference we can make for our children by attending!

Make a donation for World Heart Day and help us reach the RCGP conference! We've set up a dedicated [JustGiving fundraising page](#) so YOU can HELP get us to Glasgow, where the event is being held. We want to get Kawasaki Disease known and considered by all – including our GPs! We know you do too! #GetUsToGlasgow

We're working to raise £3,000 to cover our shortfall for this project and we'd be so grateful if you could consider a donation to help protect tiny hearts! EVERY donation counts, no matter what size! Or perhaps you'd like to fundraise yourself? Why not tackle that fundraiser you've been planning and help us reach this target! [Get in touch](#) and pledge your support!

LET'S PROTECT TINY HEARTS FROM KAWASAKI DISEASE! #GetUsToGlasgow

Get involved in protecting tiny hearts!

World Heart Day is the perfect time to raise awareness of Kawasaki Disease and protect tiny hearts! So, why not get involved? Help us make plans, take part and let's make World Heart Day a HUGE success.



Why not have a **KAWASAKI CONVERSATION OVER COFFEE AND CAKE** in your local community, or just with friends! What a brilliant excuse (if we needed one...) for eating CAKE!!! Whilst raising funds to protect tiny hearts! Download your fundraising pack [here!](#)



Or why not hold a **WEAR RED DAY** at work, or at your child's school or nursery? Make a statement in RED to help fundraise and get this sinister disease known! Download your fundraising pack [here!](#)

The Societi Virtual 10K – do it your way!

Of course, our flagship annual Virtual 10K event is back for 2023 – BIGGER and BETTER than ever! Run, walk, hop, skip or jump your way to Kawasaki Disease Awareness!

Entry costs £25 and includes a Societi t-shirt and our brand new water bottle to help you raise vital awareness of Kawasaki Disease whilst completing your walk/run in your community.

Why not download our Societi Virtual 10K poster pack and get your community involved! [Just click here!](#)



AND.....All participants will also receive a special 50% discount code to use in our Societi shop!



AND free entry into a lucky dip for a chance to win prizes including wristbands, stationery and a Societi hoodie!

[SIGN UP HERE!](#) Just complete the form and follow the link to pay for your entry!

**Donate
here!**

**What have we
been up to?**

**What have YOU
been up to?**

Get involved!