



Sandra Quinn Chris Martin

Co-Editor's Welcome

Dear Support Groups,

We are delighted to bring to you our fourth Myeloma UK Support Group e-Newsletter. We want to highlight your successes and provide information that we hope will assist you to build and sustain your Group.

In this issue, we shall hear from Dorothy Gonsalves who started a new Group at Kingston Hospital, Surrey, Sarah Rossiter the Support Group Leader in Bristol, update you on the latest service developments, and tell you about our face-to-face and virtual visits to Support Groups in 2020. We have a special interview from Sir Frank Chapman (Vice Chair on our board) who talked about his fundraising efforts during lockdown.

On behalf of Myeloma UK, we wish you all a happy holiday and a safe and prosperous 2021.

Chris Martin

Co-Editor



Leader Spotlight

Support Group Leader Dorothy Gonsalves talks about her experiences of developing a new Myeloma Support Group in the Haematology Day Unit at Kingston Hospital in Surrey. You can find out more about Dorothy and read her story inside **(Pages 3-4)**.

Leader Spotlight:

Sarah Rossiter, the current Bristol Support Group Leader, discusses why she became a Leader, what makes the Bristol Myeloma Support Group so successful, why she has found it so rewarding and what support she provides to her members (Page 9).



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Call the Myeloma Infoline on
☎ **0800 980 3332**

Visit our website at
🖱 **myeloma.org.uk**

Tell us about your Group

We are always delighted to hear from Support Groups and aim to use this newsletter to highlight your Group's activities, tell you more about Support Group Leaders and members, any success stories you have and to actively find ways of supporting you to become the best Group you can be. If you would like to feature in the newsletter or tell us about your activities, however big or small, please let us know and we will arrange to have your stories featured in the newsletter.

Leader Spotlight



Dorothy's Bio

Dorothy was diagnosed with myeloma in July last year. Like many people, Dorothy had never heard of myeloma before and was diagnosed late. By that time, many of Dorothy's bones were damaged.

In early August last year, Dorothy embarked on weekly chemotherapy for six months and attended the hospital every Monday. Dorothy recognised that she rarely came across other myeloma patients. That made it difficult to talk to others in the same position.

When Dorothy did talk to others at her appointments, she rarely saw the same people, making it difficult to build up a rapport.

Dorothy is very grateful to Lesley Chamberlain, the lead nurse at her hospital, for recommending that she attend the Infoday in London last November. She said "it was a revelation."

Dorothy Gonsalves is 69 years old and a retired civil servant. She decided to set up a Support Group with the help of Myeloma UK. The first meeting took place in March 2020. This is Dorothy's story.

The Support Group that I lead is called the Kingston Haematology Patient Support Group. It is a joint initiative with the Haematology Unit I attend and is patient led. Late last year, the staff at the Haematology Unit in Kingston Hospital consulted with their patients to ask whether they wanted a Support Group. The response was a resounding "yes". Following that consultation, hospital Patient Support Services, gave us the go ahead to establish a Support Group. The first meeting was held on 10 March 2020.

I am grateful to Lesley, our lead nurse for suggesting I attend the Myeloma Infoday. It was wonderful to chat to others who had been on similar journeys. Lesley was keen on developing a Support Group for the Unit as a whole and her support has been invaluable. I offered to run the Group. As a retired civil servant, I can use the skills I developed in my career and have the time available to do so.

As a Support Group Leader, I feel a sense of responsibility to support people when they get in touch with me. I often ask myself, "am I saying the right things?" I try to use my experiences to show people there is light at the end of the tunnel, that is very satisfying.

Having spotted my contact details

on the Myeloma UK Support Group website, one patient rang out of the blue from another hospital. Her reaction to treatment had been so severe, she had to stop altogether. Without saying, we both knew what the outcome would be. I think she just needed someone to talk to during a bleak moment, but she didn't want to keep in touch afterwards, which you had to respect.

I have done a lot of volunteering since retirement and you always get more out than you put in. It is very satisfying when you are able to make a difference. Looking back on the last seven months, the Support Group has enriched my life considerably. Despite our COVID-19 restrictions, I feel close to the members, admire the way everyone gets on with their treatment and aim to lead a full life. I feel I have something to offer because I have been through the gamut of delayed diagnosis, spinal collapse, peripheral neuropathy and infection. I also know what it is like to be a myeloma patient with failing kidneys, taking chemotherapy for six months, and lenalidomide to control my myeloma. In addition to these various issues, I know what it is like to live with myeloma on my own.

Despite all these challenges, I enjoy a good quality of life. I am very active and have many interests. I feel closer to my family and friends than I have been in the past. I also feel blessed for each and every day and value the peer support I now receive from the members of the Group attending meetings. I now talk to the nurses, Chaplains, Macmillan staff, and the wider cancer staff and patients. It really has been transformative.

Member Spotlight contd.

Whilst I am relatively new to the role, I have learned seven key things that a Leader must foster to make the Support Group a success:

- i) The human contact – sharing experiences with others who know what it is like to have a blood cancer
- ii) Providing a safe environment for members to discuss their anxieties and fears
- iii) Clear boundaries – ensuring everyone knows how to behave in the Group and be respectful to others attending meetings
- iv) Sharing useful information and contacts
- v) Being approachable and supportive
- vi) Using a variety of approaches to communicate with members (talking to members via telephone or during a walk outside)
- vii) Having a sense of humour

We were fortunate to launch our meetings just before lockdown. Our lead nurse, Lesley, was able to attend the first meeting and that was crucial as she knows all the patients. We also had the Chaplaincy visit us at the same time. Only a few patients attended, but it gave us the opportunity to agree on the parameters and expectations of our membership.

I circulated full minutes of the meeting as a record of what had been agreed and how we were going to operate. That has been shared with new members who have since joined the Group. We haven't been able to meet in person since that initial meeting, but we have frequent contact with each other in various ways.

I produce a monthly newsletter that I send out to members via email and provide printed copies that I post out to members who do not have access to IT. At the beginning, it gave practical advice on shielding and food deliveries. Since then we have included information on therapies, nutrition and short member case studies. The Kingston Hospital website is being revamped and a description of our Haematology Support Group will feature on the website; hopefully with a link to the latest newsletter. We are now at the point where we have produced seven issues.

We are fortunate that the Group can meet in the new haematology unit that is in a brand new building. It is comfortable, airy and has a lovely balcony. We have held a lunch in my back garden whilst adhering to the social distancing rules. Recently, we have tried a Zoom meeting and we have formed a small WhatsApp group. I also work closely with the Macmillan Cancer Support Manager at Kingston who is very active and we greatly value her support.



This is the balcony at the Haematology Unit

The manager at Macmillan and I sit on the Patient Partnership Group at the hospital that is chaired by the Deputy Director of Nursing. I am one of the patient representatives who attends their two monthly virtual meetings and report on the progress of the Group. This has been beneficial as we are able to get a wider perspective across the cancer network and raise our profile.

How important is Myeloma UK to your Group members?

The majority of members are myeloma patients, though the other blood cancers are represented. I raise awareness of Myeloma UK events, such as the recent presentation for relapsing and refractory patients. I make sure I attend all the events and report back to the Group. There is a lot on the Myeloma UK website about Support Groups, the email contacts for other Leaders, and contact details for Support Groups that Chris Martin oversees. I thought that the first National Virtual Support Group Meeting on 30 October 2020 was a great success and brought Support Groups and members closer together.

The Myeloma UK website is very helpful as it provides all the publications we need and helps myeloma patients to make the right choices. The contact details for the Myeloma Infoline and the Ask the Nurse services can also be found via the website. Myeloma UK also involves patients and families in research and patient advocacy to ensure the patient voice is heard. I always advise new members with myeloma to check out the website. Some patients don't want to know about the details of their myeloma, treatment and prognosis, which is fine. However, I feel I should mention these resources so that I can be supportive.



Face-to-Face Meetings

Before lockdown, I visited the Borders Myeloma Support Group where the Group talked about running a pub quiz to raise money for Myeloma UK. I enjoyed visiting the Edinburgh Myeloma Support Group at the Salisbury Arms. During my visit to the Portsmouth Myeloma Support Group, I had the tough job of following a great presentation by Dr Rob Ayto (Consultant Haematologist). However, it was a pleasure to meet so many members. I also visited the newly developing Kent and Canterbury Haematology Support Group, led by Stephanie Goodchild (Clinical Nurse Specialist). Whilst COVID-19 has made it challenging for them to develop, there has been a lot of interest in pushing that forward. Cornwall Myeloma Support Group discussed fundraising at local farmers markets and a bike ride. Finally, I would like to thank Suzanne Renwick (HCP Project Manager) for visiting the Surrey Myeloma Support Group.



Virtual Meetings

We had many face-to-face Support Group visits planned for 2020, but they were cancelled almost overnight as the COVID-19 pandemic progressed. However, our truly inspirational Support Groups started to hold virtual meetings through Zoom, Skype and on WhatsApp. The adaptation to holding meetings in this new digital environment has been truly remarkable and an inspiration to all of us at Myeloma UK. At the beginning, many of you faced some hurdles, but once you got to grips with the technology and through perseverance, you have truly succeeded in holding vital meetings. Some Groups are keeping in touch via telephone and regularly checking in on one another to see what everyone has been up to. I am very pleased to say that a number of Groups have been holding virtual coffee mornings and meetings. Whilst we all look forward to seeing each other face-to-face, virtual meetings look as though they will need to continue for now.



National Virtual Support Group Meeting

As mentioned previously, we held an inaugural National Myeloma UK Virtual Support Group meeting in October. I can't thank all of our presenters and attendees enough for making this such a brilliant meeting. We heard from our Chief Executive, Laura Kerby, and two of our colleagues presented at the meeting. Jill Williams (Patient Information Officer) and Daniel Cairns (Patient Advocacy and Policy Officer) talked about the process of developing publications and access issues to vital treatments for myeloma, respectively. At the end of the presentations attendees were split into smaller virtual "rooms" to allow members and leaders to get a chance to chat with each other. 24 Support Groups were represented at the meeting, from Aberdeen to Guernsey. I am also very pleased to say we had representation from the Group in Limerick too.



Get in touch

if you want us to visit you in the future

 0800 980 3332

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HCP Update



**By Hannah Parkin,
Senior HCP Project Officer**

GPs are the first point of contact for many cancer patients. Some patients will find their GP quickly suspects myeloma based on symptoms or blood test results, but others have their symptoms attributed to unrelated conditions. This is understandable given the vague nature of many myeloma symptoms, but can create delays in diagnosis and increase the risk of serious complications that result in an admission to A&E. This is why, at Myeloma UK, we want to provide GPs with the knowledge and tools to diagnose all myeloma patients promptly and efficiently.

The new GP Myeloma Diagnostic Tool assists GPs in recognising myeloma symptoms, highlights which tests they should request, and how to best interpret the laboratory results. The Tool highlights those patients who require urgent referral to the hospital and those who require a less urgent pathway.

For example, many patients with monoclonal gammopathy of undetermined significance (MGUS) could be managed locally by their GP, giving myeloma patients a faster route to be seen in haematology.

The Tool is designed as a traffic light system; a format routinely used in GP surgeries to indicate urgent (red) vs less-urgent (green) onward investigation.

Creation of the GP Myeloma Diagnostic Tool has been carried out as part of the Myeloma UK Early Diagnosis Programme (read more [here](#)), in collaboration with the Myeloma UK Early Diagnosis Steering Committee. The Committee is made up of hospital specialists, laboratory scientists, GPs and guest speakers who meet throughout the year to discuss the challenges of making a timely myeloma diagnosis and how to tackle these issues. A subgroup of the Committee focuses on the role of the laboratory. We are grateful to them for devoting time to work with us to help reduce the time to diagnose myeloma.

With the GP Myeloma Diagnostic Tool in place, the next question is how we can reach as many GPs as possible. At Myeloma UK we think collaboration is key. Previously, we partnered with Macmillan Cancer Support to develop a [Myeloma Ten Top Tips](#) for GPs. Through access to the Macmillan GP network, we were able to reach many GPs across the UK. This same group of GPs have received our new Myeloma Diagnostic Tool. As Macmillan GPs have a role in educating their colleagues, we hope this will encourage GPs with the tool to share it with their colleagues.

We have also recently co-authored an article (currently under review) for the Royal College of General Practitioners (RCGP) education journal called *InnovAiT*. This journal is published monthly and the printed version reaches approximately 12,000 GP readers in the UK. Journals and magazines are an excellent way of reaching a large number of professionals at one time, so we will continue to explore other similar opportunities to raise awareness of our work.

Ultimately, we aim to have every clinical laboratory in the UK using the GP Myeloma Diagnostic Tool to report test results back to GPs. This will flag up any potential patients where a myeloma or related condition is suspected. We are working with a national organisation, responsible for quality assessment in laboratories, to make this happen. We are planning a series of educational webinars for laboratory scientists to help them better understand why this Tool will provide assistance in diagnosing myeloma earlier and more effectively.

Prior to COVID-19, hard copies of our GP resources were shared at in-person education events, including the large RCGP Annual Conference, and locally at GP education sessions.

To further promote this important Tool, we would like to ask you to take copies to your local surgeries. If you would like to order hard copies of the GP Myeloma Diagnostic Tool, please email us at this address: earlydiagnosis@myeloma.org.uk. You can also download the electronic version [here](#).



Dear fundraising team,

I always look forward to supporting Coffee Morning Month in November but with all the COVID-19 restrictions this year, I don't think I can get involved in the usual way. Is there any other way I can get involved or help raise money for Myeloma UK?

Dear Supporter

Thank you for getting in touch. The good news is that the Myeloma UK Coffee Morning Month is still happening throughout November and we'd love for you to get involved. In

2020, we are encouraging you to have a Coffee Morning "your way!" As you know it's been a very challenging year for fundraising and most of our community events have been cancelled or postponed due to COVID-19. During this time our supporters have risen to the challenge, coming up with lots of inspiring and innovative ideas to raise money and we can't thank you all enough.

The Coffee Morning Month in November has been a popular fundraiser for over ten years; bringing our myeloma community together and raising thousands of pounds to help make myeloma history. We appreciate that it will be a different way of fundraising this year, but with a little creativity there are still ways you can catch up over coffee and cake and raise vital funds for Myeloma UK!

After the year we've all had, this is the perfect excuse to take time

out, enjoy some home baking and reconnect with loved ones.

To mark the change in our usual way of doing things, we are launching our '**Coffee Must Go On**' campaign and whether you go virtual with friends, gather a small group together (ensuring you follow the latest government guidelines), or just donate what you would usually spend on takeaway coffee – we would really appreciate your support.

You can get in touch with us by telephone (0131 557 3332) and we'll send you a fundraising pack, t-shirt and some delicious Lavazza coffee to get you started (see [here](#) to register). It is also really easy to donate through our Coffee Morning Month JustGiving Page (see [here](#)). Finally, we would appreciate it if you could share the link below on social media.

<https://www.justgiving.com/campaign/CMM2020>

Interview with Sir Frank Chapman



Sir Frank Chapman and his wife Lady Kari Elin

Sir Frank Chapman was diagnosed with myeloma, 'fortuitously', in December 2010 during a blood test for an unrelated issue. We caught up with Sir Frank to find out about his fundraising efforts for Myeloma UK.

How did you receive the news that you had myeloma?

"Understandably, the diagnosis came as a shock as I was living a busy and active life at the time. I was working then as Chief Executive of BG Group plc – quite a full-on role. Because the diagnosis was made at a very early stage, I was asymptomatic and required no immediate intervention, aside from close monitoring. By June 2012, things had moved on with my serum free light chain

reaching 1500 mg/l and I was inducted with Velcade and dexamethasone that led on to my first autologous stem cell transplant (ASCT) in January 2013.

I was still working full time until the end of 2012 and I remained without symptoms during that time. The ASCT got me through to 2016 when my light chains started increasing once again and I was inducted in the second half of 2016 with daratumumab, which was stunningly effective from the very first infusion. I had my second ASCT in April 2017 and have been on daratumumab maintenance

"Understandably, the diagnosis came as a shock as I was living a busy and active life at the time."

Sir Frank Chapman Interview Contd.

since then, which has held me in a very deep and stable remission. I still have no symptoms and feel very fortunate.”

How did your myeloma diagnosis impact your family?

“My family were devastated, especially my four children. It was very scary at first. Hearing that you have an incurable haematological malignancy and the possibility of having a shorter life expectancy is understandably hard to get your head around.

Looking back on my journey, I think about how far things have evolved for many myeloma patients with the advent of new treatment combinations, especially biological therapies that can replace chemotherapy in some cases. I've been lucky to be living in this era with access to new treatments. I want to keep working to ensure that all myeloma patients can share that same hope for the future.”

Why do you feel it is important to fundraise for Myeloma UK?

I am a Trustee of Myeloma UK. The COVID-19 crisis has impacted the organisation twice over: a severe diminution of fundraising caused by event

cancellations, as well as heightened demand for support services to help myeloma patients and families weigh the risks of the pandemic against their treatment and their wellbeing.

To help the charity raise vital funds, I decided to walk 1,000 km with the aim of raising £10,000 this year. It took me 59 days to complete my walk, and the furthest I walked in one day was 52km. I've actually managed to raise over £15,000, including Gift Aid. I've continued to cross my fingers in the hope that the total may even get a bit higher before it closes.

I hope that the funds I raise will help Myeloma UK continue to support myeloma patients and their families during the COVID-19 crisis. Being able to fund ongoing programmes in patient advocacy, such as working to ensure that new and often expensive emerging drugs are accessible through the NHS, is of vital importance to me.

It is also crucial that any funds that are raised continue our mission to provide healthcare professionals with educational

materials and accredited training. It will also assist Myeloma UK to invest in research developments, such as genomic profiling to identify high risk patients for priority treatment.”

You are clearly keen for more supporters to get involved in fundraising for Myeloma UK. How do you think our supporters can get involved?

“Get yourself organised and have a go. You will be surprised at the support there is out there for people suffering from this disease and their related conditions, who are ready to get behind the work of this brilliant blood cancer charity.”

Contact the Fundraising Team to find out how you can get involved

Fundraising@myeloma.org.uk

“... I think about how far things have evolved for many myeloma patients with the advent of new treatment combinations...”

How you can help us raise vital funds for Myeloma UK?

Every penny counts and it makes a difference to our work as we continue to support myeloma patients and their families with everything a diagnosis brings.

Christmas Cards

It's hard to believe that Christmas is just around the corner! An easy way to support Myeloma UK at this time is to buy Christmas Cards. There's a great range of designs this year and you can order online [here](#).

Myeloma UK Weekly Lottery

You can also join our lottery and be entered into our weekly draw with the chance to win an amazing £25,000! It costs just £1 a week to enter – with at least 50p from every £1 coming directly to support

Myeloma UK. The odds are good as the likelihood of winning a prize is 1 in 63. You can find out more and sign up [here](#).

We really appreciate all you do especially considering the challenges the COVID-19 has brought to our lives, so thank you for continuing to support us where you can and help us make myeloma history.



Leader Spotlight

My name is Sarah Rossiter and I live in North Somerset with my husband and a cat named Doris! I work for an independent TV company in Bristol in the finance department.

The Bristol Myeloma Support Group was set up in 2007 by Myeloma UK. We hold our evening meetings in a community room in Horfield, Bristol. There have been a number of different Leaders between then and now, each taking on the role in a slightly different way.

My mum and I attended our first Support Group meeting just after my dad was diagnosed with myeloma in 2011. We met fellow patients and family members at the meeting. At the beginning my dad rarely came to the meetings, but as time went on he realised the meetings would give him an opportunity to chat and become friends with members of the Group. Very sadly, my dad passed away just over 3 years ago.

I was first asked to be treasurer of the Group, paying our rent, organising “floats” for our fundraising stalls at the local hospitals, as well as paying funds into the bank account and sending regular donations to Myeloma UK.

I was asked to take over running the Group in 2017. I decided to run it slightly differently as I was working and knew I wouldn't

have the time to do it all by myself. We got together as a team to make decisions about future meetings, potential speakers, where we wanted to go on our days out and other related issues. With the help of Myeloma UK, we have produced an annual leaflet for local hospitals to provide details of our future meetings for each year.

I write a bi-monthly newsletter and ask for contributions from other Group members; hearing from each other makes it a more interesting read! Our newsletter helps us to communicate with members who might not regularly come to meetings, but would like to know what's going on with the Group.

We also changed over to monthly meetings, with a more formal evening meeting once a month and a speaker and a coffee morning the following month. However, we had to change things the way we do things this year!

We normally have two fundraising events every year at the local hospital, where we sell cakes, biscuits and homemade gifts. Since 2017, we've donated nearly £1,000 to Myeloma UK in addition to donations made to our local hospital. We have an annual New Year meal together, and a day out,

which the Group funds for myeloma patients.

The team work hard to promote our Group at the two large hospitals in Bristol, but we find it difficult to encourage new members to attend. We don't have a dedicated CNS working with us at the hospitals, and we feel the support we get from the hospitals is sketchy at best. This is the most frustrating part of running the Group. However, it is really rewarding to see genuine friendships develop in the Group. That's where the support comes; from each other. It doesn't matter if you're a family member or patient. The “chatter” at the beginning or close of every meeting is lovely to hear and be part of.

I continued to lead the Group after my Dad passed away, as I saw it as a positive thing to do; offering support to others. I have now decided to pass the baton on to someone new, perhaps someone who will galvanise the hospitals into being involved in the invaluable work a Support Group can offer.

If you would like to take over the Leader role in the Bristol Myeloma Support Group, please get in touch with us at Myeloma UK.



Bristol Myeloma Support Group on their annual summer outing in 2019

Thoughts for the day...

“Support Groups are particularly necessary to myeloma patients during the Covid-19 pandemic. Try to keep in touch virtually though Zoom and WhatsApp. Give it a try!”

Alan Chant, Trustee, Myeloma UK and Group member



“We are grateful to Support Groups for bringing the myeloma community together to share personal experiences, coping strategies and first-hand information of the disease and treatment. Knowing local support is available is reassuring. Thank you.”

Laura Kerby, Chief Executive



“I am really impressed by the caring and supportive network that Support Groups provide to one another. They truly are a life-line for patients and families and provide such comfort and support at what can be a challenging time.”

Claire Holmyard, Individual and Planned Giving Manager



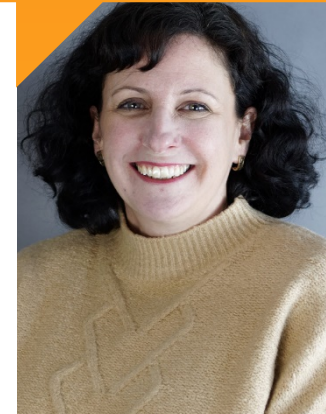
“I direct patients and family members to Support Groups where they will find the peer support they need. The role Support Groups play in overcoming challenges is essential. Thank you for your continued support and hard work.”

Sarah Dempsey, Myeloma Information Specialist



“Support Groups provide an opportunity for myeloma patients to meet and share experiences, access practical and emotional support from their peers and from healthcare professionals; all of the people who understand you best.”

Mairi Needham, Finance Assistant



Please get in touch if you have thoughts you would like to share with other Groups

📞 0800 980 3332

✉ newsletter@myeloma.org.uk

Lost in Lapland

Join us on our Festive Virtual Mission



Santa has lost Buddy the Elf, Rudolph and a sack of presents somewhere in Lapland. Can you help guide them back to Santa's Village in time for Christmas Eve?

Sign up to complete either **10km, 50km or 100km** distance in whatever way you like between 1-24 December.

Find out more and sign up at
www.myeloma.org.uk/lostinlapland

Myeloma UK is a registered charity, no. SC026116

Myeloma Stars Christmas Appeal is back for 2020

Last year, supporters like you helped us raise nearly £20,000 by donating and dedicating stars to the special people in your lives on our Myeloma Stars website.

Your donations support our vital work with myeloma patients. Please help us shine again this Christmas by dedicating a star.

Dedicate your star now!

[Visit MyelomaStars.com](http://MyelomaStars.com)