

RVH LIVER SUPPORT GROUP

Who we are & what we do

- The RVH Liver Support Group was founded in 1998 by Kay Duffy in response to an acute need for support before, during and after a lifesaving liver transplant of a loved one.
- The Group is exclusively focused on helping those with liver disease and their families in N Ireland.
- Run by a small committee of volunteers from around the Province, there are no paid staff, ensuring that a very high proportion of the funds donated goes directly to patient care and the provision of medical equipment.
- **Patient Care:** First and foremost, the principal objective of the Group is to provide compassionate, emotional and psychological support to those patients with liver conditions and their families using personal contact or phone calls in an atmosphere of mutual respect.
- **Fostering Mutual Support:** The Group will always seek to provide opportunities for patients with a liver condition to offer mutual support to each other. This is usually achieved through regular members' meetings, and a range of organised external events around the Province designed to encourage discussion and friendship among patients and their families.
- **Provision of Medical Equipment:** Donations given are used to buy much needed pieces of equipment as requested from time to time by the Liver Unit in the RVH and the Outpatients clinic, for the benefit of patients.
- **Financial Support:** The Group can, following strict and agreed guidelines, provide a limited level of financial assistance to patients who have to travel outside N Ireland for assessment, transplantation or other liver related treatments.
- **Patient Helpdesk:** a manned helpdesk is provided in 6B Outpatients lobby during adult liver clinics in the Royal Victoria Hospital, together with regular attendance at the joint liver clinic at the Royal Belfast Hospital for Sick Children.
- **Promotion of Awareness of Liver Disease:** The Group continuously raises the awareness of liver disease in its many forms.
- **Organ Donation Register:** The group takes every opportunity to promote the register and its benefits in support of those in need of a transplant.
- **RVH Liver Consultants & Team:** The Group works hand in hand with the liver consultants, transplant co-ordinators, ward staff, specialist nurses, dietitians and specialist physiotherapists in the Royal Victoria Hospital and supports them in every way possible.

HOW TO DONATE

There are many ways in which the public can generate funds for the Liver Support Group. These include: -

- Via the group website www.rvhliversupportgroup.org
- Via social media - "Just Giving" is a versatile way of raising funds from your friends, colleagues and family. Further information can be found here - www.justgiving.com/start-fundraising
- Cash donations
- Legacy fundraising – donations 'in memoriam' following a bereavement
- Raffles
- Quizzes
- Marathons
- Dinners
- Public collections

If invited, a member of the Liver Support Group Committee will always be happy to attend fundraising events for cheque handovers, and to speak about the various ways in which the Group supports those with liver conditions in Northern Ireland.

Being a small Committee without the resources to arrange our own fundraising, we are always very appreciative of all of the efforts that fundraisers undertake in organising and running events on our behalf.

Gift Aid Guidelines

This is a method of tax relief used by many charities. The scheme allows charities to claim back 25% of the tax already paid on all eligible donations made by a UK taxpayer (a taxpayer who has paid at least the same amount as the Gift Aid amount in the same tax year as the donation). Gift Aid can also be claimed on donations made via Just Giving. It is highly recommended that all donations are subject to "Gift Aid" thereby increasing donations received by 25%. There is no additional cost to the donor. Further information on this can be found here - <https://www.gov.uk/donating-to-charity/gift-aid>.

A Charity Gift Aid declaration form needs to be completed and this gives the Liver Support Group permission to claim the Gift Aid amount. A digital version of this form is included in this communication entitled "Charity Gift Aid Declaration".

Some types of fundraising won't be eligible for Gift Aid e.g. funds raised from cake sales, auctions and sale of tickets. More information can be found at - <https://www.gov.uk/claim-gift-aid/what-you-can-claim-it-on>.

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FUNDRAISING POLICY

Fundraising Regulations

There are some general rules that all fundraisers need to follow, such as making sure that all money raised goes to the cause it was raised for, and also some specific ones that are relevant for particular forms of fundraising such as public collections or running a raffle. The “Code of Fundraising Practice” (effective October 2019) brings together all of these rules, both legal requirements and best practice standards, and can be viewed or downloaded here –

<https://www.fundraisingregulator.org.uk/sites/default/files/fr-code/Code%20Fundraising%20Practice%20October%202019.PDF>

Anyone who is considering fundraising for the Group is strongly encouraged to familiarise themselves with these rules, and to find out which might apply to their preferred form of fundraising.

PUBLICISING YOUR EVENT

Here are a few ideas for getting the best out of your event, whether you want to encourage people to attend, let others know what you are doing, or raise awareness of the RVH Liver Support Group.

➤ **Online**

If you are using a fundraising page, keep it up to date with your plans. Use social media to update people quickly and regularly. You may want to write a blog, or send a weekly email to people who are supporting you.

➤ **Press Release**

One of the easiest ways of getting media coverage for your event is to write a press release.

- Include the 5 “Ws”: who, what, where, why and when and state if you have a personal link to liver disease.
- Keep it short and punchy – no more than one side of an A4 sheet
- Attract attention with a catchy headline/strap line
- Make it clear if you want the public to attend
- If you can, include a photo – you are more likely to get media coverage. Have someone on hand to take high quality digital images to send to local newspapers
- Remember to include your contact details and some information about the Liver Support Group.

➤ **Tell us about your plans**

We can help promote your event on our Facebook page - www.facebook.com/rvhliversupportgroup

➤ **In the Community**

Ask if you can promote your event at the library, local gym, community centres etc. Think about where you have seen events advertised and see if you can get ads for free.

➤ **Friends and Family**

Email your friends and family. They will be the ones supporting you throughout - make sure they know why you are doing this and recruit some key members to be your support crew! Don't be afraid to ask for help.

➤ **At Work**

Ask if you can promote your charity fundraising on your work newsletter or intranet. Does your employer have a “match funding scheme” that you could tap in to?

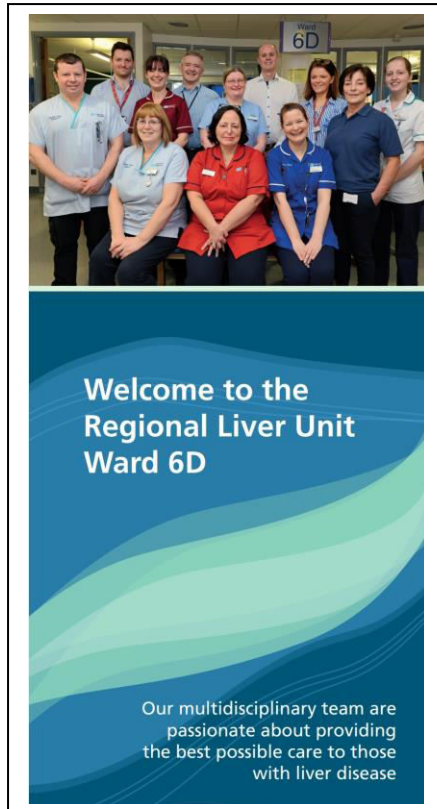
➤ **After the Event**

If your local media can't promote your fundraising before the event, send a follow up story with a photo of the event, or if they did promote it, send a thank you letter to say how much money was raised and thank those who took part. Thank your supporters by email and online. Don't forget to also let us know so that we can show the results on our social media.

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TESTIMONIALS



The Regional Liver Unit based at the Royal Victoria Hospital is comprised of a multi-disciplinary team led by a group of six consultants. This team provides care for adult and adolescent liver patients across Northern Ireland including care for patients with acute or chronic liver failure, complex bile duct disease, viral hepatitis, liver transplantation and a wide range of chronic liver conditions.

The RVH Liver Support Group has been supporting the Regional Liver Unit in delivering a high level of care to patients and their families across all of Northern Ireland since 1998. The Group regularly support the education of staff, provide medical equipment to enhance patient care or comfort and have previously supported research projects.

Dr Johnny Cash, Hepatology Consultant

Since the RVH Liver Support Group was formed, they have provided profound support to the staff on the liver ward, ensuring we are never without the specialised equipment we need to provide a regional liver service.

We greatly enjoy the in-ward visits to patients undertaken by Jim and Kay, as they provide invaluable support and information to patients and their relatives going through the transplant process, offering comfort and answering questions that only they can provide empathetic answers to. We feel we also learn from hearing about their journeys.

The Liver Support Group fully stock the information leaflets on the ward to ensure patients and relatives have up to date and relevant facts when needed. The leaflets provide the patients with an understanding of their conditions as well as how they can gain access to further support if they need it. Not only do we appreciate the information and services provided, but we definitely enjoy Kay and Jennifer's home baking when they call to see the team.

During the Covid19 pandemic especially, the Group helped maintain our safety by providing much needed PPE at a time when stocks were low. They also sourced other short supply items when we have asked them for assistance. As a unit we rely heavily on the Liver Support Group - to us they are an extension to our liver family in the RVH.

Team 6D Staff

As a family we first came into contact with the Liver Support Group after our son had his first liver transplant. We exchanged numbers at the RVH and a follow up call from one of the Group's carers was transformative. Since our child had suffered acute liver failure, the unexpected promotion to the role of carer was traumatic, exhausting and often overwhelming. A friendly and compassionate conversation with someone who had not only lived but survived the story was a godsend - a sense of hope laden with empathy.

In summary, what LSG means to our family –

A friendly chat. A genuine recognition of you, your child, and your story. A shared and mutual understanding. Whether by phone/text, attendance at RVH clinics, link-ins with Birmingham

TESTIMONIALS

Children's Hospital's specialist support nurses, sometimes that familiarity in the clinical setting is so comforting.

The Group's ethos is to promote and encourage shared support – e.g. the family events spring to mind at the Share Centre and Olympia Leisure Centre fun day. Bringing families together in alternative settings, allowing them to relax, enjoying some freedom and fun away from the realities of an often stressful existence. It is nice too to meet families who walk your path. There is a certain solidarity in sharing stories of the fight.

Financial support is such a hugely helpful bonus in the armoury of the group. Living in hospitals is expensive. Juggling a family at home is expensive. Trying to navigate time out of work whilst nursing a child in hospital breeds worry, fear even. The mortgage, the overheads, the cost of the daily grind. The Group offer financial support (discreetly) and under strict guidelines, and it often arrives unexpectedly but is so welcomed. A helping hand when it is needed most. We can never thank the Group enough for their personal and familial support. They have walked by our side. We are buoyed by our walking partner - every step of the way.

Maeve Curley

I first became aware of the work of the Liver Support Group during a visit to Outpatients when I picked up some literature they provided at their Helpdesk, and had a chat with one of the volunteers. As my disease progressed towards transplant I found the group invaluable. They are literally there for you 100% of the way. From literature and guidance to answers to the numerous questions you may have. They provide moral support and motivation, having helped so many others before you. The Support Group literally IS a lifeline when you feel you are the only one going through the trauma of liver disease.

When my time came for transplant assessment they used their experience to make the whole process easier for me. From which taxi firm to use when travelling to Kings to actual practical help with expenses. The moral support, knowledge, empathy and kindness provided by the group was a godsend to me and my family at a time when our courage was low.

It doesn't stop there though. Thanks to the efforts of numerous fundraisers each year, in addition to all the support to the patients, the Group provides numerous items of equipment to the Outpatients Department as well as Ward 6D which cannot be funded by the NHS.

Of course none of this comes at any financial cost to us as patients/family. The RVH Liver Support Group is a registered charity providing its services to those in need. As such they need all the help they can get. As a family we are proud to assist in their fundraising efforts. It is our way of saying 'Thank You' because, believe me, we are forever grateful for everything they did for me personally and us as a family.

I had often heard of the great work carried out by the RVH Liver Support Group. Having now experienced it first-hand I can honestly say that every single penny they receive from fundraising is very wisely and very carefully spent for the benefit of patients and the medical professionals alike.

I implore every one of you to do what you can to fundraise. You never know when any of us will need the Group's services.

Eilish McAteer