

**ROYAL VICTORIA HOSPITAL
LIVER SUPPORT GROUP
NIC100892
ANNUAL REPORT FOR 2024**



Registered Address

Crievemoy, 8 Dungannon Street, Moy, Dungannon, BT71 7SH

Trustees

Kay Duffy, Jim Kilpatrick, Rachel Quinney-Mee, Sharon Millen, Patricia Getty, Arthur Goan, Ashley Collins, Jane Megahy

Basis of Reporting

This report covers the activities of the Group for the calendar year 2024. The Group's AGM was once again held via Zoom on Thursday 21st March. All members received invitations to attend, including those for whom we don't hold an email address, to ensure all members were aware of the meeting. Members attending were issued with all relevant AGM papers by email in advance of the meeting, namely the Agenda, 2023 Annual and Financial Report, and a summary of the Accounts for 2023.

Committee

At the AGM all offices were declared vacant. All existing Committee members were willing to continue serving in office, and were duly re-elected.

Election of Office Bearers

In line with the procedure laid down in our Constitution, the Chairman, Vice Chairman, Treasurer and Secretary were elected into office by the Committee members at their first meeting following the election of the full Committee at the AGM. These were Chairman – Jim Kilpatrick, Vice Chairman – Arthur Goan, Treasurer – Jim Kilpatrick, Secretary – Ashley Collins.

Bereavements

We remember the members of our Group who unfortunately passed away during this reporting period and pass on our condolences to their families.

Meeting our Stated Objectives

The work of the Group continues to be driven by the stated objectives in our governing document and as ever, any review and evaluation of our work must assess how well we have fulfilled those objectives in the past year.

1) To foster an atmosphere of mutual support and encouragement among people suffering from liver disease and their carers, families and friends.

The AGM was held on 21st March by Zoom, with the election of Committee members being conducted by Dr Neil McDougall, who also brought those participating in the meeting up to date with news from the Liver Unit. As with our other Zoom meetings, members from across all parts of the Province participated. There are many practical benefits and efficiencies in holding our AGM online, something the Committee have considered for future AGMs.

Following the initial success of our occasional coffee mornings in the Autumn of 2023, the Committee set about planning venues across the Province for the rest of 2024. These included the Seagoe Hotel in Portadown, the Mourne Country Hotel in Newry, Woodlawn Garden Centre in Carryduff, the Everglades Hotel in Derry/Londonderry, Mossley Mill in Newtownabbey, the Stables in Groomsport, Hillsborough Castle (to coincide with Organ Donation Week). More are planned on an ongoing occasional basis at selected venues around the Province.

Our annual Members' Lunch was held in early June, this time at the Tullyglass Hotel in Ballymena, when we were delighted to have over 100 members, family members and friends along for a most enjoyable full buffet lunch. Many positive comments on the venue, and the quality and quantity of the food on offer, means we are planning a return in June 2025.

We were delighted to be able to hold a Family Christmas Party in December, which was thoroughly enjoyed by the children and young people present, as well as their parents and family members. The afternoon was filled with art and craft activities, party food, and a visit by Santa Claus. Everyone is looking forward to a repeat in 2025.

All of the events above allow us to bring our members together socially, providing them with opportunities to mutually support each other through friendship and the chance to understand what each other has gone through in their own personal liver disease journey. We should not, however, lose sight of the primary purpose of the Group, patient and family care and support. This continues discreetly in the background, away from public gaze. One to one private support of patients and their families occurs via text messages and phone calls, often at unsociable hours, but always with the aim of providing the best possible support that we can in any particular scenario.

Many hours are spent each month by the team of Kay Duffy, Jim Kilpatrick and Arthur Goan assisting and supporting adult patients and their carers, with the same commitment shown by Rachel Quinney-Mee and Patricia Getty in their support of children and adolescents with liver conditions, and their parents.

During 2024 those committee members with responsibility for patient care made 465 contacts with adult patients and carers, and 198 with the parents of children. Most of these have been sustained contacts over difficult and sometimes distressing periods of time. Patient care remains the core element of our work and we continue to carry it out in a very dedicated and dignified way.

As well as practical and emotional support, we continue to offer financial assistance to patients travelling outside Northern Ireland for liver-related procedures, pre-transplant assessments or transplantation. For the financial year to 31st December 2024, we paid out £25,100 in patient support grants (2023 - £23,600). The majority of payments (34) were for procedures or treatment for children and young people, 26 were for pre-transplant assessments, with 22 being paid after successful transplantation. In addition, £500 was spent on bereavement grants, to help support the immediate family circles of deceased patients.

2) To raise awareness of liver disease in all its forms for the benefit of the public.

Our Helpdesk presence outside 6B Liver Outpatients in the RVH has had a full year of operation, following its restoration in late 2023, after the lifting of Covid restrictions. We are once again interacting with patients attending their appointments as they attend their checkups. A number of leaflets from the British Liver Trust are once more on display, as well as Group contact information. Clinics are now held each day, with the principal pre- and post-transplant clinics on Tuesday and Thursday mornings, usually with no more than 8 to 10 appointments. We look forward to chatting

with patients as they come and go - if you are passing by for an appointment, please do stop and say 'hello'.

Throughout the year the joint clinics between Birmingham Children's Hospital and the Children's Hospital have continued, and we were able to see a level of normality once again. These opportunities for direct face to face contact with families are pivotal occasions to meet and support them during difficult times, and for parents of new patients to learn about the support the Group can offer them. Thanks go to the staff in the Children's Hospital for their support and cooperation during the joint clinics.

During the year we began attending the occasional joint King's/RVH clinics held in Ward 6D, where we are able to inform the attendees about the Group, and offer advice and support to those being seen. This cooperation with the medical team is greatly appreciated by them and the patients alike.

During 2024 our Facebook, Instagram and Twitter channels, as well as our own website, were a vital means of disseminating updates from the Public Health Agency, Organ Donation NI, the British Liver Trust, as well as from the RVH Hepatology Consultants, and our own Group-related activities and information.

We were delighted to see the return again of the British Liver Trusts' 'Love Your Liver' Roadshow to Northern Ireland in September, this time for a 4-day visit. This gives the public the opportunity to have a free Fibroscan check in the Roadshow trailer. We were delighted to support the Liver Trust staff in managing the queues waiting for their scan. It was an extremely busy time, with over 500 people scanned in Londonderry, Belfast, Enniskillen as well as at Stormont Buildings, of which around 7% received advice on following up their scan with their GP. We look forward to the Roadshow returning in 2025, and have pledged our continued support to the British Liver Trust once again.

We were extremely fortunate throughout 2024 to be one of the chosen charities of Cllr. Mark Cooper BEM, during his year in office as Mayor of Antrim & Newtownabbey Borough Council. This afforded us the opportunity to make the Group more visible across the Borough, and to avail of every opportunity to meet with Council officials and staff, and those residents we met at social events during the year. The highlight was undoubtedly the Black Tie Ball, held in March at the Hilton Hotel, Templepatrick, especially in support of the Group. Our thanks go to Mark and his team for their very substantial donation to the Group during his term in office.

3) To support by means of financial assistance ... persons suffering from liver disease through research or the provision of equipment or facilities.

The replacement of the Ward 6D portable ECG monitor, ordered at the end of 2023, due to it suffering an increasing number of operational failures, was completed in 2024, and is now in use in Ward 6D. The staff are delighted at the timing, as it has now been calibrated to feed directly into the Epic Encompass system for patient records, which went live in June.

The refurbished Relative's Room in the Glasshouse on Ward 6D is now proving to be an invaluable asset, being used by patients, family members, and Ward staff. It is also a quiet space for the Consultants to discuss the care of patients with their families. Supplies of tea, coffee, sugar, milk and biscuits are continually restocked as necessary.

At Christmas, individual adult patient gift bags were made up, comprising a selection of foodstuffs, confectionery and toiletry items, along with a variety of crossword, sudoku puzzle books and pens. The child patient hamper was filled with individually packaged 'goodie bags' containing reading books,

note pads, drawing books, puzzle books, pens and other small items to keep them all busy and active. Some toiletries were also included for the teenagers. Our thanks go to those on committee who spent considerable time putting these together. Everything was gratefully received and hopefully brought a smile and a little pleasure to those unfortunate enough to be staying in hospital over the Christmas period.

We ended the year with a new method of offering support to vulnerable adult patients arriving into the liver Ward directly from the Emergency Department, many of whom arrive with no personal items. We now supply Group-branded personal washbags, containing vital necessary personal hygiene items such as a toothbrush, toothpaste, shower gel, cleansing wipes, lip balm, deodorant, facecloth, and for the men, shaving gel and a razor. The ladies receive some moisturising face wash, skin moisturiser and some hygiene pads. These washbags have been very well received by both the patients and the Ward staff caring for them, who appreciate the 'feelgood factor' which comes from receiving quality branded items as part of their care. We will continue to keep the Ward stocked with these washbags in the future.

4) *The promotion of the organ donor register.*

The Group has always espoused the benefits of organ donation and organ transplantation in all its forms, and we take every available opportunity to promote those benefits through all possible means. While this happens throughout the year, it reaches a peak during Organ Donation Week in September.

We were able to share honest, loving recollections from our members about how their lives have been positively changed due to organ donation, this time via some personal video interviews with patients. Everyone commented on the enormous sense of gratitude they feel towards their donor, their decision to donate their organs, and the fact that they'd had 'the chat' with their families about their decision. Committee members also engaged directly with local Councils as they once again supported Organ Donation Week. Our social media posts during Organ Donation Week were widely shared and copied by many organisations in support of organ donation, such as Organ Donation NI. Photographs of the Group's activities regularly appear in local newspapers.

With Daithi's Law - the Organ and Tissue Donation (Deemed Consent) Bill - now up and running, there can be no relaxation in our role of encouraging the public at every opportunity to have 'the chat' with their family and friends, and to sign the Register so that in the event of their death, their decision is clearly registered and known, thus making consent for donation by their family at that time, more clear cut. The Law has changed organ donation to a system where all eligible adults, normally resident in Northern Ireland, will be deemed to have consented to donate their organs in situations where it is possible for donation to occur, unless they specifically indicate their desire to be removed from the Organ Donor Register.

It is disappointing however that previously ring-fenced finance put in place by the Stormont Executive to continue to advertise the change to the law, has now been rescinded. We can only hope there will be no long term reduction in the public's awareness of the change, and that their willingness to consent to organ donation remains strong.

Ongoing work

The core work of the Group continues to be undertaken by our small dedicated team of Committee members, spread geographically across Northern Ireland, who keep our primary goal of support and care for liver patients and their families and friends to the fore at all times. Each member has their own particular responsibilities, ensuring we operate efficiently for the collective benefit of the whole Group.

As ever, our Founder Kay Duffy leads the Adult Patient Care team, with the same care and attention to detail as she has done for the many hundreds of patients who have been supported over the years.

Sharon Millen, acts as our liaison with the Charity Commission, our link with all matters of academic research into liver disease and psychology, and our coordinator for the Belfast Marathon and patient participation in the British, European and World Transplant Games.

Arthur Goan, in addition to his role as Vice Chairman of the Group, maintains our contact database of members and manages our website. He is also responsible for Adult Patient Care, sharing this with Kay Duffy and Jim Kilpatrick. This involves manning the Helpdesk at Liver Outpatients and also ensuring the Relative's Room is clean and restocked with tea/coffee and other supplies. He also focuses on specific areas affecting our liver patients such as alcohol, and hepatitis.

Ashley Collins is the Secretary of the Group, producing Minutes of our proceedings of a very high quality. She also willingly assists with activities for our children and adolescents, offering invaluable help to Rachel and Patricia when required.

Rachel Quinney-Mee and Patricia Getty, in addition to their roles as Patient Carers for children and adolescents continued their very active liaison work with the Public Health Agency on the Group's behalf. Their dedication to their role takes up many hours of their time, all of which helps foster a close relationship with the parents of the children they support.

Jane Megahy, our Social Media Administrator, continually produces high quality graphic work for our social media channels and emails, and looks after securing appropriate software to handle our bulk emails and texts to our members. With so much of our communication relying on getting the most out of technology, Jane's knowledge in this field is a great asset.

Jim Kilpatrick fulfills the roles of Chairman, Treasurer and Adult Patient Carer. His interactions with the consultants, ward staff and outside bodies is continual, and gives direction to the Group's focus and activities.

The work of the Group is extensive and wide ranging, and it is clear that we would not be able to perform our roles and provide the support we do without the ongoing and unwavering financial support we receive from fundraisers, whether patients or their families or friends, or monies we receive in the form of bequests or 'in memoriam' donations. Every single penny we receive is put to use here in Northern Ireland to further the charity's goals and purposes.

We are rightly recognised as the 'de facto' patients' voice for liver patients across Northern Ireland, irrespective of the type of condition. Our influence extends beyond our local borders, through our relationships with the British Liver Trust, King's College Hospital, Birmingham Children's Hospital, and other patient support groups across the British Isles. To that end, we were delighted during 2024 to offer advice and to pass on our experiences over the years, ahead of the creation of the new Liver Ireland Support Network (LISN), which supports liver patients in the Republic of Ireland. We wish them success in all they do in the future.

Financial Report

The total net worth of the Group at 1st January 2024 was £204,280.23, made up of our Danske Current Account £5,595.13, Danske Investment Account £68,685.10 and NI Central Investment Fund for Charities (NICIFC) £130,000. This NICIFC investment equated to 9,008 shares in the Fund, which with

a share price on 31st December 2023 of £15.0637 meant our shareholding at the start of this financial year had a market value of £135,693.81.

Income

Total income for 2024 came to £110,440.29 (2023 - £81,501.89), our highest ever income thanks to several one-off donations. Of this total, £65,594.18 came from direct donations (2023 - £49,437.56). Some £34,516.63 came via Just Giving including Gift Aid on applicable donations (2023 - £19,212.74). The effectiveness of donating and fundraising via Just Giving is well known, and we find many fundraisers choose this online system for their campaigns. Thanks to all of you. Our own direct Gift Aid reclaim from HMRC produced £3,207.28 (2023 - £1,828.15).

To maximise the return on our investment monies, we increased our shareholding with the Northern Ireland Central Investment Fund for Charities by purchasing another 3,233 shares (£50,000), and now hold a total of 12,241 shares. This equates to a total investment of £180,000. Our NICIFC investment has been made with security and longevity in mind, and we will ride out any short term rises and falls which occur. In line with the Fund's long term stated aim of achieving a consistent 3% yield on investments, the dividends received from the Fund during the year, added to the much smaller Interest from our Danske Accounts, came to £5,627.20 (2023 - £4,873.44).

We must offer thanks to everyone - patients, family members and friends - who undertook sponsored fundraising on our behalf, and to those who made quiet and discreet personal donations during the year. The ingenuity and inventiveness of our fundraisers is amazing to see, and never fails to impress.

Expenditure

Total expenditure for the year came to £54,581.68 (2023 - £70,864.81), of which £25,100 was Patient Care payments (2023 - £23,600). The reduction in expenditure compared to 2023 is due to there being no further outgoings during the year in connection with the Group's 25th Anniversary. Nor was there any spend on new equipment for the Liver Unit, as this was not requested during 2024.

Committee travel expenses, vital to ensure the Committee members can effectively undertake Group business across the whole of the Province, came to £4,240.47 (2023 - £3,232.40) and reflected a marked increase in demands for attendance at fundraising events, committee meetings, members' meetings and other Group organized events. No committee expenses are paid unless approved beforehand and fully receipted. We provide a summary of all of the expenses incurred, per person, to the Charity Commission as part of our annual submission of our accounts.

Telephone and postage charges reduced significantly to just £249.76 (2023 - £795.99) thanks to changing our phone contract to a new low cost provider, and maximising our use of electronic communications with our members. Printing, Leaflets & Stationery also saw a sizeable decrease to £1,668.44 (2023 - £3,696.86). As with all planned expenditure, quotations were received and considered by the committee before any purchase. Reflecting the large increase in the number of coffee mornings organised during the year, together with our annual Members' Lunch, expenditure for Members' Events rose to £12,090.13 (2023 - £8,240.49).

Our Public and Trustees Liability Insurance premium rose slightly again to £557.36 (2023 - £476.56). IT costs rose to £1,298.73 (2023 - £313.88), covering the charges for software licences and maintaining our website, plus our new bulk text service subscription. Maintaining consumables (tea/coffee/biscuits/milk/sugar) in the Relatives' Room in Ward 6D came to a total of £2,111.25.

Our annual return visit to King's College Hospital was in September. These visits, by the Patient Carers on the committee, are vital in ensuring we keep up to date with any personnel or operational changes at the hospital, and allow us to build and develop relationships with those people our patients are most likely to encounter when they travel to King's for either assessment or transplant. The resulting benefits to those we care for are massive, and should not be under-estimated. Our 'Patient's Guide to Visiting King's College Hospital' - a handbook for patients from Northern Ireland who need to attend King's, was reviewed and updated during the visit. It provides essential information about how to get to King's, accommodation options, and travelling around the area to and from the hospital. This will continue to be reviewed annually and updated as required to ensure it remains current at all times. Total expenditure for the visit was £2,328.68 (2023 - £1,811.16).

The year finished with a total net worth of £260,138.84, made up of our Danske Current Account £1,017.63, Danske Investment Account £79,121.21 and NI Central Investment Fund for Charities (NICIFC) £180,000 (historical cost). As referred to earlier, the NICIFC investment market value at 31st December sat at £190,678.06.

It should be noted that the administrative costs of running the Group are fully covered by our investment income and Gift Aid reclaims, meaning every single penny of personal donations or monies received by fundraising efforts, goes to patient care, member events and supporting the medical staff's work in supporting patients.

Conclusion

In many respects, 2024 was something of a record year for the Group's finances, as well as our range of operations. With our financial security, the Committee will continue to explore new avenues of patient care, which would have been unthinkable even five years ago.

With our Helpdesk service at the transplant clinics back in full operation, and our presence increasing at various other clinics, along with our ability to visit patients in Ward 6D, our aim is to constantly improve our patient support, and to react to the suggestions and wishes of our members. We hope to be able to grow our support at the joint clinic at Altnagelvin, and expand our interactions with the Gastroenterology unit in the Ulster Hospital. We will continue to search out early patient engagement opportunities at the other regional hospitals across the Province, in order to be able to support liver patients early in their journeys.

I am known to state frequently how immensely proud I am of how our Committee works diligently in their service to the Group's members, and with a strong commitment to their roles, this will continue for some time. Their work however is for nothing without the desire from the members to support all we do, not only through involvement in our meetings and activities, but also through their continued financial support. We can only do what we do, because you enable us to do so.



Date: 31 January 2025

Jim Kilpatrick MBE
Chairman / Treasurer / Adult Patient Carer