

ROYAL VICTORIA HOSPITAL
LIVER SUPPORT GROUP
NIC100892
ANNUAL REPORT FOR 2023



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 2023. The Group's AGM was once again held via Zoom on Thursday 16th 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, 2022 Annual and Financial Report, and a summary of the Accounts for 2022.

Committee

At the AGM all offices were declared vacant. All existing Committee members were willing to continue serving in office.

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.

Election of Committee Members

Existing Committee members Kay Duffy, Rachel Quinney-Mee, Sharon Millen, Patricia Getty and Jane Kilpatrick were re-elected.

Bereavements

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

Strategy Meeting

A Strategy Meeting with the RVH Liver Unit Consultants and staff was held in late September, where we discussed matters of mutual interest affecting the Liver Unit such as patient care, equipment provision and future plans by both the Liver Unit and ourselves.

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 16th March by Zoom, with the election of Committee members being conducted by Dr Neil McDougall, who also brought those participating 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.

This was followed, on 29th April, by the principal event during the year to mark the Group's 25th Anniversary. Two years preparation and planning went into the Anniversary Dinner, plans made initially in the throes of Covid restrictions, when it was difficult to project how things would look by 2023. But we need not have worried, as on the night almost 280 people filled the Ballroom in the Crowne Plaza Hotel at Shaw's Bridge in Belfast. This was the same venue used to mark both the 10th and 20th Anniversaries, and the staff certainly prepared the rooms perfectly for us. Attending were clinicians and nursing staff from Belfast and London, members of the LISTEN Support Group in King's College Hospital, and most importantly, our local liver patients and their families. Old friendships were renewed, and many tales from years gone by were related, while it was also the perfect opportunity for members to form new friendships with fellow patients. It was a huge success.

After the Summer break we once again arranged a Members' Lunch in the Dunsilly Hotel, where over 80 members and friends enjoyed a fine three course meal, and the opportunity to meet together in person again. As everyone arrived they could take the opportunity to view some of the beautiful vehicles parked out front from the Masonic Historic Vehicle Club, as well as have a chat with members of the Belfast Advanced Motorcyclists, who had stopped by for coffee on their Sunday run. Once again there was plenty to chat about and catch up on between those who knew each other, while many new friendships were created as people introduced themselves to their fellow diners. Drew Melville, who had provided the music at our Dinner in April, joined us again to entertain us while we ate and for a few dances afterwards. It was great to provide the opportunity for everyone to socialise informally and enjoy some quality time together.

Having polled our members, they told us that they would like the chance to meet together from time to time outside of formal events such as the AGM and Members' Meetings where we have invited speakers address the members. We began in August with our first Coffee Morning, held in Bangor, where a total of 25 attended throughout the morning. It was exactly what we were hoping for, and those present looked forward to the next one in the area. This has subsequently been followed by one in Coleraine, as well as in Omagh and Enniskillen. More are planned on an ongoing occasional basis at selected venues around the Province.

We were honoured that the Mayor of Ards and North Down Council, the Mayor of Antrim and Newtownabbey Council, and also the Chair of Mid Ulster District Council, invited those Group members living in their respective Council areas to private receptions to mark our 25th Anniversary. Their ongoing support for the work of the Group is most welcome.

The Brunswick Moviebowl in Londonderry saw a large turnout in November for the Family Fun Day, allowing parents and young children to come together for some friendly competition, some tasty food and the chance to meet new friends. Judging by the photographs on our social media, it was a great success.

We concluded our 25th Anniversary year events with a first for us - a Service of Thanksgiving for the Group, its Officers over those years, and the gift of life brought about by organ donation. This was

held in the Chapel of Unity in Methodist College, Belfast, in late November, and featured addresses by Kay Duffy OBE (Founder), Dr Sharon Millen (Past Chairman), Dr Roger McCorry (RVH Hepatology Consultant) and Canon Rev Kevin Graham (Deputy Lieutenant for the County Borough of Belfast), as well as quite fantastic music provided by Jonathan Rea, Rebekah Durston and Steph Devlin. Also participating were Cllr. Mark Cooper (Mayor of Antrim & Newtownabbey), Patricia Getty, Gerry Kelly and Dylan Caughey. Officiating was Rev. Janice Browne, and the welcome came from Chairman Jim Kilpatrick. Without doubt, for many, the highlight came when all organ recipients present were invited to come forward to light a candle in memory of their donors.

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 2023 those committee members with responsibility for patient care made 335 contacts with adult patients and carers, and 191 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 2023, we paid out £23,600 in patient support grants (2022 - £13,750). The majority of payments (37) were for pre-transplant assessments, rather than actual transplants (11). When these assessments may translate into transplants is obviously unknown, but it will be a large backlog to handle.

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

After some three years' absence, we were finally given permission to partially restore our Helpdesk operation outside 6B Liver Outpatients. This initially entailed just a small foldaway table, but by November our full desk was returned to its rightful place, much to the pleasure of the Outpatients' staff, and ourselves. We can now once again interact with patients attending their appointments. A number of leaflets from the British Liver Trust are once more on display, as well as Group contact information. Clinics are now held on Tuesday and Thursday mornings, usually with no more than 7 or 8 appointments, unlike the very large clinics in pre-Covid days. Nevertheless, we are back in person at each one, ready to speak to existing members and to introduce ourselves to new patients.

Throughout 2023 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 2023 our Facebook, Instagram and Twitter channels 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. Our members actively participate in the British Liver Trust's regular Zoom wellbeing meetings. These popular hour long drop-ins are an ideal opportunity for local liver patients to join with others from around the UK to mutually support and inform each other about both liver and personal matters of interest.

We were delighted that after a lengthy absence, the British Liver Trusts' 'Love Your Liver' Roadshow returned to Northern Ireland in May, for a 3-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 340 people scanned in Londonderry and Belfast, of which around 10% received advice on following up their scan with their GP. We look forward to the Roadshow returning in 2024, and have pledged our continued support to the British Liver Trust once again.

In October our Chairman, Jim Kilpatrick, represented the Group at the release of the British Liver Trust's Liver Cancer UK report into the state of liver cancer across the UK, held in the Palace of Westminster. Opportunity was taken to discuss this with local MPs Carla Lockhart and Jim Shannon, and to lobby them for action and support in moves to reduce instances of liver cancer by better education and provision of better screening services in Northern Ireland.

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

The annual Strategy Meeting enables the Committee to consider requests from the Liver Unit for financial assistance with particular pieces of research or for items of equipment. Following a successful trial of ELF Tests which we purchased in 2022, we have now financed a further 100 tests at a cost of £5,000 to assist in reducing the NAFLD referral list while long term approval for their use is secured by the Trust.

Following an additional request, we also financed the replacement of the Ward 6D portable ECG monitor, due to it suffering an increasing number of operational failures. We originally provided this equipment to the Ward back in around 2008, and in the intervening period technology has progressed so much that the old monitor was barely recognisable compared to others in adjoining Wards. The new, much more effective and easier to use version was secured at a cost of £9,270.

To mark both the end of Covid restrictions, and also our 25th Anniversary, a full refurbishment of the Relative's Room in the Glasshouse on Ward 6D was carried out. The remaining old furniture was removed and replaced by a new 3-seat recliner settee, and recliner armchair. New side tables were also bought, along with a lamp. On the kitchen side, a new coffee maker was purchased, along with a microwave, cups, cup racks and supplies of tea, coffee, sugar, milk and biscuits. Each week we will monitor the cleanliness of the Room and restock the consumables as necessary. Initial setup costs were £1,592.48. The Room has seen regular use, with the facilities being much appreciated by families spending a considerable time with ailing relatives on the Ward. It is also a quiet space for the Consultants to discuss the care of patients with their families.

Having begun in 2021, we once again prepared and delivered Christmas gifts to both the Children's Hospital and the main RVH Hospital during the week before Christmas. Hampers for the staff in the Children's Hospital and Outpatients were specifically filled with items they could use in their rest rooms and kitchens - tea, coffee, sugar, biscuits, and festive foodstuffs, as well of course, as packs of Cadbury's Heroes!

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.

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. 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.

We were present once again at Stormont in early June for the official launch of Daithi's Law - the Organ and Tissue Donation (Deemed Consent) Bill, which now brings Northern Ireland into line with the rest of the UK in changing the essence of 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.

With the Law now in place, and operation of it underway, 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.

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, and our link with all matters of academic research into liver disease and psychology.

Arthur Goan, in addition to his role as Vice Chairman of the Group, maintains our contact database of members and manages our website. He also took on responsibility this year 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.

Ashley Collins is the Secretary of the Group, producing Minutes of our proceedings of a very high quality. Unfortunately, due to family pressures, Ashley had to temporarily step back from her role for the latter part of the year, with the preparation of Committee Minutes picked up by Sharon in her absence.

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 produced high quality graphic work for our social media channels and emails, and looked after securing appropriate software to handle our bulk emails out to our members. We were delighted that in March she also found time to marry Michael, and we wish them well in the years to come.

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.

In our drive to continually improve our efficiency, and to react quicker to requests for support, we have adopted a more 'corporate' approach to our operations. This has resulted in us standardising much of our publicity material using defined colours across the board. We have invested in new logoed clothing for the Committee, new leaflets, business cards, posters, pull-up banners and other items which project a uniform perception of the Group wherever we happen to be.

Financial Report

The total net worth of the Group at 1st January 2023 was £193,643.15, made up of our Danske Current Account £6,454.43, Danske Investment Account £57,188.72 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 2022 of £14.2380 meant our shareholding at the start of this financial year had slightly decreased in value to £128,255.90, due to the depressed market at the time.

Total income for 2023 came to £81,501.89 (2022 - £83,339.72), a very creditable total compared to last year's record. Of this total, £49,437.56 came from direct donations (2022 - £50,446.23). Some £19,212.74 came via Just Giving including Gift Aid on applicable donations (2022 - £27,262.34). 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 £1,828.15 (2022 - £606.09).

With our long term shareholding in the NICIFC now sitting at 9,008 shares - a total investment of £130,000 - we were not immune to the impact of both the general post-Covid rise in living costs, and the damaging worldwide financial downturn caused by the Russian invasion of Ukraine. In common with most share prices, the value of our holding remained under pressure during 2023, but the Fund

management are predicting a return to better times as we enter 2024/25, and the various holdings are amended to produce better yields for shareholders. Our NICIFC investment has been made with a long term view in mind, and we will ride out any short term rises and falls which occur. Nevertheless, 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, plus the Interest from our Danske Accounts, came to £4,873.44 (2022 - £4,140.06).

Total expenditure for the year came to £70,864.81 (2022 – £46,472.39), of which £23,600 was Patient Care payments (2022 – £13,750), plus £16,137.48 for the tests, ECG monitor and the refurbishment of the Relative's Room detailed previously.

An increase in Committee expenses to £4,688.63 (2022 - £1,681.97) reflected a significant increase in travel to meetings, especially those in connection with our 25th Anniversary events. Other Committee expenses are paid against essential spend on necessary committee business, and aside from mileage for attendance at Group events, is occasionally paid when a committee member incurs other necessary costs such as for postage, or consumables at a members' meeting, personal printing costs such as printer ink, or for gratuities, namely vouchers, presented to speakers at our members' meetings as thanks from the Group. Pending receipt of a debit card on the Group account to facilitate the ongoing purchase of supplies for the Relative's Room, a personal account was used for the initial purchase of some of the furniture, and the provisions up to the end of the year. This has adversely skewed the overall Expenses total as a result. 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 increased to £795.99 (2022 - £642.99) mostly due to several bulk mailings in relation to Anniversary events, plus the issue of tickets to members for the Anniversary Dinner. Printing, Leaflets & Stationery saw a sizeable increase to £3,696.86 (2022 – £1,044.16) as we updated and reprinted leaflets, restocked our pens, purchased several types of new banners, and restocked our stationery. Much of this was expended in relation to Anniversary events and other publicity materials post-Covid. As with all planned expenditure, quotations were received and considered by the committee before any purchase. The cost involved in attending meetings came to £666.51 (2022 – £217.36), including attending the Liver Cancer UK report release at Westminster.

Our Public and Trustees Liability Insurance premium rose slightly to £476.56 (2022 - £462.30). IT costs were capped at £313.88 (2022 - £663.88), mostly the charges for software licences and maintaining our website.

We were able to arrange another essential return visit to King's College Hospital in August. 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. The major outcome from this year's visit was the completion of our 'Patient's Guide to Visiting King's College Hospital' - a handbook for patients from Northern Ireland who need to attend King's. 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 be reviewed annually and updated as required to ensure it remains current at all times. Total expenditure for the visit was £1,811.16 (2022 - £2,129.42).

Once again, we had great support from our members who participated in the Belfast Marathon (though with this falling on the morning after our 25th Anniversary Dinner, there were some very tired people at the end)! Their sponsorship is always welcome.

Member events increased again as we left Covid behind. These included, not just participation in the Marathon, but also our Members' Lunch once again in the Dunsilly Hotel, Antrim, in September, when over 80 members and friends enjoyed the opportunity to meet, chat and make new friends face to face. Following feedback from our members, we began a series of on-going coffee mornings, paid for by us as a result of your fundraising. In addition, providing tea/coffee/biscuits and cleaning materials for the refurbished Relatives' Room has resulted in total expenditure on members' events rising to £8,240.49 (2022 - £4,499.02).

After Patient Care and the provision of Hospital Equipment & Services, our 25th Anniversary events saw the highest expenditure during the year, covering the 25th Anniversary Dinner and Service of Thanksgiving. The net spend of £6,180.89 on our 25th Anniversary events is derived from the sum of the expenditure for these in 2022 (£1,045.00) and 2023 (£10,785.89), offset by income for tickets in 2022 (£560.00) and 2023 (£5,090.00).

The year finished with a total net worth of £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 (historical cost). As referred to earlier, the NICIFC investment market value at 31st December sat at £135,693.81.

Conclusion

2023 brought the Group's operations back to full tilt once again. Overall income reached £81,501.89, including the exceptional income related to the 25th Anniversary, with total expenditure coming to £70,864.81, resulting in a net increase in the worth of the Group of £10,637.08. We are in a very sound financial position, able to move forward with our plans for 2024 and beyond.

Having seen the resumption of our full Helpdesk service at the Outpatients Clinics, and our ability to visit patients in Ward 6D, our aim is to constantly improve our patient support, and to react to their suggestions and wishes.

On a personal note, I was privileged to be awarded the honour of Member of the Order of the British Empire (MBE) for services to people with liver disease and their carers across Northern Ireland, in the King's New Year Honours List 2024, an award I accept on behalf of the Group. I state frequently and loudly, 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. Our 25th Anniversary year is now behind us, here's to the next 25.



Date: 16 January 2024

Jim Kilpatrick MBE
Chairman / Treasurer / Adult Patient Carer