

TRUSTEE ANNUAL REPORT FOR THE YEAR ENDED 31ST MARCH 2024

MEETING PROGRAMME

OUR WEEKLY ZOOM MEETINGS ON A TUESDAY ATTRACT APPROX 12 PEOPLE PER WEEK, AND WE HAD 3 GUESTS DURING THE YEAR. THEY WERE THE PCC (PATIENT AND CLIENT COUNCIL) DR INGRID HOERWITZER AND PROFESSOR STONE. THESE SESSIONS WERE ATTENDED BY APPROX 30 PEOPLE WHO LISTENED TO EXCELLENT DISCUSSIONS AND THE FEEDBACK WAS MORE THAN POSITIVE.

OUR DROP-INS CONTINUED AT LEAST 1 PER MONTH AT DIFFERENT LOCATIONS SUCH AS BALLYMENA, BELFAST, LISBURN, MAGHERAFELT, NEWTOWNARDS AND PORTADOWN. AT LEAST 15 PEOPLE WERE IN ATTENDANCE PER SESSION.

OUR YOUNG PEOPLES & YOUNG ADULTS ZOOM CALLS MET ONCE A FORTNIGHT AND AT CHRISTMAS WENT BOWLING TOGETHER. THEY ALSO MET DURING THE YEAR WITH AN ARTIST WHO ALSO HAS FND AND PRODUCED A VIDEO EXPLAINING ABOUT THEIR CONDITION AND HOW THEY COPE WITH IT.

THEY WERE ALSO PART OF A GROUP AT STORMONT WHEN A DELEGATION OF YOUNG PEOPLE SPOKE TO MLA'S ABOUT THEIR CONDITION AND THEIR EXPERIENCE WITH THE HEALTH SERVICE. THEY EXPLAINED THAT NO PATHWAY FOR FND PATIENTS WAS AVAILABLE AND THAT THEY HAVE BEEN TREATED POORLY BY HEALTH PROFESSIONALS AS A WHOLE. THEY EMPHASISED THE NEED FOR BETTER PAEDIATRIC SERVICES FOR YOUNG FND PATIENTS.

FEEDBACK FROM ALL THE ABOVE WAS MORE THAN POSITIVE AND WE ARE ESPECIALLY DELIGHTED ABOUT THE YOUNG PEOPLE AS THEY SEEM TO HAVE BONDED OVER THEIR SHARED CONDITION. THEY HAVE ALSO PROVED TO BE GREAT FUNDRAISERS AND HAVE RAISED SEVERAL THOUSAND POUNDS FOR FND MATTERS NI.

COUNSELLING

OUR COUNSELLING SERVICE IS GOING WELL. THE 4 COUNSELLORS SPEAK TO APPROX 10 CLIENTS PER WEEK. SINCE WE BEGAN OFFERING FREE COUNSELLING FROM FND TRAINED COUNSELLORS, TO DATE WE HAVE RECEIVED OVER 170 APPLICATIONS. SOME OF THESE CLIENTS HAVE BEEN REFERRED TO US BY HEALTH PROFESSIONALS BUT UNFORTUNATELY WE HAVE BEEN UNABLE TO SECURE FUNDING FROM THE DEPT OF HEALTH. FORTUNATELY WE HAVE SECURED £20,000 FROM THE NATIONAL LOTTERY, AS THE YEARLY COUNSELLING COST IS WORKING OUT ABOUT £23,000. WE WERE INFORMED BY PROFESSOR STONE THAT FND MATTERS NI IS THE ONLY FND CHARITY TO PROVIDE THIS VALUABLE AND MUCH NEEDED SERVICE.

TRUSTEE MEETING PROGRAMME

TWO TRUSTEES HAVE BEEN INVOLVED IN QUITE A FEW NETWORK MEETINGS AND ARE PART OF THE ALL PARTY GROUP ON NEUROLOGY AT STORMONT. WE WERE ABLE TO EXPLAIN THAT NO PATHWAY IS AVAILABLE FOR FND PATIENTS AND THAT THEY FELT THEY HAD BEEN DISMISSED BY MOST HEALTH PROFESSIONALS. THIS WAS TAKEN ON BOARD BY THE MLA'S.

WE ARE MEMBERS OF NINCA (NORTHERN IRELAND NEUROLOGICAL CHARITIES ALLIANCE) AND ATTEND MEETINGS ONCE A MONTH. MEMBERS INCLUDE MS SOCIETY, STROKE SOCIETY, BRAIN INJURY AND PARKINSONS, ALONG SIDE OTHER NEUROLOGICAL CHARITIES. THE ALLIANCE FOCUSES ON THE HEALTHCARE SYSTEM AND HOW BROKEN IT IS.

OUR INPUT HAS BEEN VITAL WITH THE NEUROLOGY REVIEW AS ALONG WITH DR NIGEL LYTTLE WE HAVE BEEN INSTRUMENTAL IN PLANNING A PATHWAY FOR FND PATIENTS. A PUBLIC CONSULTATION HAS BEEN PLANNED AND FOR THE FIRST TIME EVER FND HAS BEEN MENTIONED AND A PATHWAY WILL BE PUT IN PLACE WHEN MONEY FROM THE DEPT OF HEALTH BECOMES AVAILABLE.

JEANETTE IS A MEMBER OF THE FND SOCIETY WHICH INCLUDES PROFESSIONALS FROM A NUMBER OF COUNTRIES IN THE WORLD. THEY HAVE REGULAR MEETINGS AND PRESENTATIONS FROM WORLD FND SPECIALISTS.

WE ARE MEMBERS OF THE NEURO ALLIANCE CO-PRODUCTION WORKING GROUP AND INSTRUMENTAL IN THE 'BACK THE 1 IN 6 CAMPAIGN.

PLANS FOR 2024-2025

DISCUSSIONS HAVE BEEN TAKING PLACE BY THE TRUSTEES ABOUT PLANS FOR GOING FORWARD. WE HAVE DECIDED TO HOLD ANOTHER CONFERENCE WITH THE EMPHASIS ON ENCOURAGING HEALTHCARE PROFESSIONALS TO ATTEND, AS FND IS OFTEN MISUNDERSTOOD. SUGGESTIONS FOR SPEAKERS WERE PUT FORWARD AND WE TENTATIVELY SUGGESTED IF WE COULD GET A PAEDIATRICIAN AS THE MAIN SPEAKER AND POSSIBLY SOMEONE FROM SPEECH AND LANGUAGE AND A PHYSIOTHERAPIST WOULD BE IDEAL.

A PROPOSAL FOR PUTTING TOGETHER A PLAN TO FORWARD TO THE DEPT OF HEALTH FOR FUNDING IS IN THE EARLY STAGES. THIS WOULD INVOLVE ASKING FOR PARTICIPANTS WHO HAVE ATTENDED OUR COUNSELLING SERVICE AND LIVING IN THE BELFAST TRUST AREA TO GIVE CONSENT TO ACCESS THEIR MEDICAL RECORDS BY A HOSPITALCONSULTANT AND TO PRESENT TO THE DEPT OF HEALTH AS EVIDENCE THAT FND MATTERS NI OFFER A SERVICE THAT MAKES A DIFFERENCE TO THE LIVES OF THOSE LIVING WITH FND.

FUNDING

WE RECEIVED SEVERAL GRANTS DURING THE YEAR INCLUDING ONE FROM THE NATIONAL LOTTERY FOR £20,000 TO BE USED SPECIFICALLY FOR COUNSELLING.

WE HAVE PARTNERED WITH ENTHUSE WHICH IS A FUNDRAISING PLATFORM AND THIS HAS CREATED SOME FUNDING AND THE NEW YEAR WILL SEE US TRYING TO OBTAIN MORE FUNDING AND GRANTS.