

## **Directors Report 2015 to 2016**

### **New Board Member**

At the Annual General Meeting on 21st June 2016 Maddie Collin was formally appointed as a member of the board of the Association. As a young adult with Type 3 Gaucher disease Maddie will be able to bring a different perspective to the board and will be able to provide a voice for our younger members.

### **Advocacy Service**

#### **a) Patient & Family Support Worker**

The Association provides a dedicated Patient & Family Support Worker that provides support and advice to meet the non-medical needs of the Gaucher community in England, Scotland and Wales. Type of support provided includes:

- Telephone Helpline
- Advice on Welfare/Disability Benefits
- Advice and support on Educational issues
- Advice on Housing and equipment
- Projects – supporting and developing projects to support families, young people and young adults with Gaucher disease.
- Employment advice, Curriculum Vitae support, work experience placements
- Attending clinic appointments with patients at their request and hospital specific Gaucher clinics
- Attending hospital Gaucher clinics to meet patients and family members and talk to them about the Association

#### **b) All Ireland Advocacy Worker**

Through a partnership agreement with the Society for Mucopolysaccharide Diseases, the Gauchers Association provides our Irish members and their families an advocacy service to act as a support network, to bring about more public awareness and to promote and support research. Alison Wilson, a genetic counsellor based at Belfast Hospital in Northern Ireland, has been working as an advocacy worker for the MPS Society since 2011 and in 2013 her role was extended to cover patients and families with Gaucher disease.

### **Raising Awareness of Gaucher Walk**

On Sunday 1<sup>st</sup> May the Association organised a 5-mile circular walk in the Cotswold to raise awareness and money for the Charity. 60 walkers from the local area including patients, family members and friends enjoyed the walk and then afternoon tea. Each participant was given a t-shirt to wear to raise awareness of the disease and the work of the charity.

### **Members Survey**

As part of the Association commitment to meet the needs of the UK Gaucher community an online survey was set up to capture information on how the Association is currently meeting the needs of its Members, to assess our Members awareness of the work of the Association and to identify what the members would like to see the Association provide. The survey was also amended and distributed to healthcare professionals and Industry partners to capture information on how effective the Association is in working with them to meet the needs of the

Gaucher community. The results of the survey will be published later in 2016 and will form part of the Association's strategic development programme over the next 3 years.

### **GD 1 Information Booklet**

Funding for a new Type I Gaucher disease booklet was awarded to the Association. The booklet is being developed in conjunction with the Association's Members who have completed an online survey to identify the topics and areas of interests to them and their families from initial diagnosis to living with Gaucher disease. This booklet will be published in early 2017.

### ***New Patient Day***

The Association arranged a fun day at LEGOLAND, Windsor in 2016 for all the new families who hadn't yet met each other (as well as meeting members of the Association). Ten families with newly diagnosed children attended the day which gave them the opportunity to get to know each other and make friends. Three young adults with Type 3 Gaucher disease also attended to meet the families.

### **National Highly Specialised LSD Service**

#### ***Gauchers Centres and National Specialised Services***

We would like to thank all the clinicians, the Clinical Nurse Specialists and the teams at each of the centres for their continued advice and support to the Association and their dedication to Gaucher patients. The national service provides our members with the very best treatment. The adult centres work with the paediatric centres in helping patient transition from childhood to adulthood.

#### ***LSD Expert Advisory Group (EAG)***

As patient representative, Tanya Collin-Histed sits on the EAG and attends bi-annual meetings with representatives from each of the LSD centres in England (and in Wales as an observer) and the NHS England Commissioning staff to discuss clinical management, guidelines, research, treatment options and other issues associated with the National Highly Specialised LSD Service.

#### **National Homecare Framework for LSDs Service**

As the patient representative for the UK LSD patient Collaborative, Tanya Collin-Histed sits on the national project team for the development of a national homecare tender for the 8 Lysosomal Storage Disorders (LSDs) specialised centres in England.

The existing homecare contract which commenced on 1st October 2015 will end in 2017 and the future provision of homecare for Gaucher and LSD patient is being discussed. Alternative more independent care models are being discussed.

### **Wales**

The Association through the Chief Executive attend meetings held by The Welsh Health Specialised Services Committee (WHSSC) and Genetic Alliance Wales to ensure that the

Association have an input into Policy development on access to medicines and shape service provision for Gaucher patients.

### **Ireland Meeting**

In partnership with Alison Wilson our advocacy worker in 'ALL Ireland' the Association had hoped to organise a Members meeting in spring 2016, financially supported by Genzyme and Shire, however this has been postponed until 2017. It is hoped that the Association's Patient & Family Support Worker and Chief Executive will attend.

### **Gaucher disease in Europe and other parts of the World**

The Gauchers Association is one of the founding members of the European Gaucher Alliance (EGA), a collaboration of patient representative groups around Europe and the World which now has 45 members (representing 44 countries). In June 2016 Members of the EGA voted for the EGA to become a Global Organisation. Tanya Collin Histed was appointed as the Chief Executive Officer of the EGA in June 2014 and Jeremy Manuel, one of the Association's directors, is a Director and former Chairman of the EGA. The EGA is operated on a day to day basis from the Association's headquarters in the UK. Tanya Collin-Histed splits her 37.5 hour working week between the two organisations.

### **Neuronopathic Gaucher Disease Type 3**

#### ***7<sup>th</sup> nGD Family Conference***

84 patients, families, healthcare professionals and representatives from the pharmaceutical industry attended the 7th nGD family conference in Manchester from Friday 13th to Sunday 15th November 2015.

During the weekend 12 children were entertained by our fantastic volunteers with arts and crafts, and a day of fun in the snow at the Chill Factore (the UK's largest indoor snow centre).

The meeting programme once again was designed in partnership with the type III girls, Irma, Maddie, Nadia, Saphia, Radhika and Sara guided by Patient and Family Support Worker Helen Whitehead with a focus on current research projects, education, lessons learnt in nGD and wearable technology. At the end of the day the young adult patients had the opportunity to sit down and test some of the wearable technology alongside Elin haf Davies, James Skinner from aparito who have developed the technology and Dr Aimee Donald, a Paediatric Neurologist from Manchester Children's Hospital who is the PI for the study. Their feedback will be used to make any necessary changes to the final version of the software that will be piloted in the New Year by the young adults to collect live data on their daily functioning. Other topics presented included; genetics, palliative care, psychology and fantastic personal stories from patients and parents.

Saturday evening gave the families and professionals an opportunity to catch up with old friends and meet new ones with a meal together.

On the Sunday whilst the children enjoyed mosaics, decorating a pencil case or bag along with games and arts and crafts, the families had a closed session looking at topics such as the Association's and UCL's Gene Therapy project and a forthcoming clinical trial for Type III Gaucher disease.

Families travelled from all over the UK as well as the USA, Sweden, and Denmark to

attend the meeting. Feedback from those that attended was extremely positive and the clear message from the weekend was 'Together we are a stronger community.'

### ***Developing Patient Related Outcomes (PROs)***

Over the past 18 months the Gauchers Association has been working with Genzyme and with Quintiles Advisory Services, a worldwide consulting firm, on a research study to better understand the experience of patients who have Type 3 Gaucher disease. The overall purpose of the study is to learn which symptoms of the disease are the most common, and how these symptoms typically affect the lives of patients who live with the disease. This understanding may help improve how the patient's experience is accounted for in clinical trials that measure the effect of disease treatments. It also may help patients and their families by highlighting the consequences of the disease that most need attention, possibly leading to new programmes and support services.

The initial one hour interview with nine GD 3 young adults has been completed and this data was analysed and identified a) the symptoms most identified by the patients and b) the impact of these symptoms on them. The next stage was to look at the current Genzyme clinical trial protocol for its new oral therapy and to identify which of these symptoms and impacts would be measured by tools already as part of the phase II trial and which were not. The next step is to look at possible tools to address the ones identified by the patients, are they already in existence or will they need to be validated? All the young adult patients have agreed to take part in a further more in-depth interview that will help support the logistics later this year.

### ***Genzyme GD III Clinical Trial***

Tanya Collin-Histed has been working with Genzyme Global to understand their approach and provide encouragement and guidance on a clinical trial (CT) that will seek to address the unmet needs of Type III for Gaucher patients. Several potential barriers regarding access to the CT by the UK patient population were identified and raised with Genzyme which initiated discussions with Genzyme and NHS England Commissioners to ensure that if eligible and willing ALL of our UK patient population could participate in the CT. To support our GD3 patient population and their families the Association sought the agreement of Genzyme to make a closed presentation by an adult Clinician at the 7<sup>th</sup> nGD Family Conference in November 2015 to discuss the clinical trial to identify who would like to be considered for the trial and to answer any questions.

### ***Orphazyme***

The Association's Chief Executive Tanya Colin-Histed was contacted by Orphazyme, a Danish Biotech Company that is interested in GD 3. They have had some very positive results regarding GD3 in the lab with their lead molecule which is already phase III enabled. In November 2015, they hosted a meeting in Copenhagen to which the Association was invited to better understand what the key issues are for patients that a new drug should address and how they might define objective and quantifiable clinical endpoints representing these issues. The Association has been assisting Orphazyme in identifying naive GD 1 and 3 patients in other countries around the world to run a 'proof of concept trial' in early 2017.

### ***Wearable Technology***

In partnership with Dr Elin Haf Davies and Dr Aimee Donald, Paediatric Clinical Research Fellow and the Gaucherite Consortium, the Association have raised the funds through unrestricted grants from Shire and Genzyme to conduct a pilot study for the use of wearable technology and mobile phone applications to assess the impact of nGD on daily living. This study will help to learn more about the condition, to encourage more research into these problems and to develop management and interventions to support patients. At the 7<sup>th</sup> nGD family Conference a presentation was made on this project and a workshop took place with the young adults to feedback on the initial areas that the data would capture, were they the right ones and were any missing. It is anticipated that recruitment will begin in the autumn of 2016.

### **Type III Information Booklet**

Funding for a new Type III Gaucher disease booklet was awarded to the Association. The booklet is being developed in conjunction with the Association's Members who have completed an online survey to identify the topics and areas of interests to them and their families from initial diagnosis to living with Gaucher disease. This booklet will be published at the 8<sup>th</sup> nGD family Conference in 2017.

***Empowering Young Type III GD Patients to Shape the Future'***: Following the second and final year of funding from a global patient advocacy leadership award (PALs) the Association received further funding for the Empowerment Project through Great Ormond Street Hospital for a further two years.

Achievements of the projects from 1<sup>st</sup> July 2015 – 30<sup>th</sup> June 2016 have been;

### ***Facebook***

Through the Association's Patient & Family Support Worker, Helen Whitehead there is an active Facebook private group for the type III young adult group. This has been a success and has improved communication between the Association and this group of young adults which has resulted in improved levels of communication.

### ***Type 3 Group meetings***

During this period the Type III young adults have met and participated in several different meetings and projects, such as;

1. A teleconference in June 2015 to work on the planning for the 7<sup>th</sup> nGD Family Conference
2. An activity week end in September in the lake District involving two of the GD 3 young adults
3. A workshop in February 2016 to further develop the wearable technology app.
4. A shopping trip at Bicester village as a social event in May 2016

5. Two GD 3 young adults travelled to Taiwan in August 2015 to participate in several Gaucher clinics and to meet other young people with Gaucher disease to further understand the challenges faced by other patients in different countries.
6. Two GD 3 young adults travelled to India in January 2016 to participate in several Gaucher clinics and to meet families with children with Gaucher disease to further understand the challenges faced by other patients in different countries.
7. One Type 3 young adult was invited to present at a Genzyme patient advisory board meeting in April 2016 to raise awareness of the challenges of living with type 3 GD as a young person

The Empowerment project is supported by Dr Derralynn Hughes and Clinical Nurse Specialist Niamh Finnegan from the Royal Free Hospital, London

### **Unexplained Deaths**

In July 2015, the Association learnt of the death of one of our young adults aged just 19 years old. This young girl and her family were well known to the Association and the families.

Following this death, the second in 2015, we lost a 14-year-old GD 3 patient earlier this year, Dr Aimee Donald, a Paediatric Clinical Research Fellow at Manchester Children's Hospital and the Research Fellow on the GAUCHERITE project contacted the Association to ask for support to look into the deaths of GD3 patients over the last few years to put together a series of case studies to look at patterns and features in their deaths This was undertaken through studying their clinic notes. The Association shared its knowledge with Dr Donald of the seven GD 3 patients that we have lost in the past 6 years. The results of this study were presented to the WORLD conference in San Diego, 29<sup>th</sup> February – 3<sup>rd</sup> March 2016, the Association's Chief Executive is a co-author on the paper.

### **Raising Awareness of GD 3**

In April, Chief Executive Tanya Collin-Histed and Board Member Maddie Collin were invited by Genzyme Europe to attend a Patient Advisory Board meeting in Holland. The purpose of the meeting was to bring together patient advocates from around Europe (representatives attended from Sweden, UK, Slovenia, Denmark, Greece and Serbia) to talk about unmet needs within the patient community with a focus on Type 3 Gaucher disease, Bone disease and the links with Parkinson's and Cancer. The format of the meeting was to hear personal stories from patients who have experience in these areas and then to discuss what current support was available to patients around these topics and what the outstanding needs were.

Tanya talked about the work of the Gauchers Association in the UK supporting patients and their families with type 3 Gaucher disease. Unlike many other European countries, the UK has a largish (in rare disease terms) GD3 community with to date 31 patients in the UK and have recognised for many years that they have huge unmet needs which we can help support them with. Maddie told her own story of growing up with type 3 Gaucher disease, the challenges she has faced but also talked about how it has made her a stronger person and enabled her to help others, to give them hope and to make a good life for herself.

## **Fundraising & Awareness**

The Association held its sixth charity cycle ride in September 2015. The 60-mile cycle was from London to Cambridge linking two of the original Gaucher centres. Sarah Allard, the Association's Charity and Information Officer coordinated the cycle ride, with support from Alan Rosen, Jeremy Manuel, Liz Manuel and a group of their friends who all gave their time for free. The event attracted over 70 cyclists and raised over £20,000 for the Association.

The Association continues to use the 'Just Giving' and 'Virgin Money' sites, which enables members and supporters to donate funds online to the Association. Members are encouraged and supported to use this method for sponsorship for all fundraising activities including the London Marathon, London 10K, Ride 100, annual subscriptions, the bike ride, and individual member activities and is proving very successful.

The Association had five runners in the 2016 London marathon raising over £11,500 for the charity and for the third year we have secured three golden bond places in 'Ride London', a 100-mile bike ride challenge, raising £1000. In 2015 we secured 5 places in the Great North Run raising £1,400 and 5 places in the London 10K raising £1,400.

2015 saw the 2<sup>nd</sup> Cricket Day organised by one of our members and his friends in Nottingham, raising £7,500 for the Association.

Other member fundraising activities included; half marathons, Ironman, 10k runs, in memory, birthday celebrations, line dancing, mini marathons, golf competitions and donations from local organisations.

The Association is extremely grateful to all its members who continue to support the charity.

## **UK LSD Patient Collaborative Group**

The patient organisations for those affected by LSDs work collaboratively within the umbrella of the 'LSD Patient Organisation Collaborative' to work and lobby on behalf of LSD patients and their families in the UK. The group is made up of representatives from the Association of Glycogen Storage Disease, Batten Disease Family Association, the Gauchers Association, the Society for Mucopolysaccharide Diseases, the Niemann-Pick Disease Group UK, Save Babies (Krabbe) and CATS (Tay Sachs). As part of this collaboration, the Gauchers Association has undertaken to jointly promote and share understanding of their diseases to advance standards of care and to enhance the well-being of those affected.

The LSD Collaborative is now a recognised forum and provides the expert patient perspective to NHS England in respect of procurement of Enzyme Replacement Therapy and Home Care and the approval of new therapies coming to the market. It also has a representative on the Metabolic Clinical Reference Group (CRG) of the NHS England.

## ***Students for Rare Disease - If you hear hooves it may be a zebra.....***

Following the success for the Collaborative in 2013 when this project was awarded a global Patient Advocacy Leadership Award (PALs) by Genzyme, the project which is a partnership between a group of Medical Students at Barts and The London School of Medicine and Dentistry and the LSD Collaborative, seeks to educate future doctors about Rare Diseases,

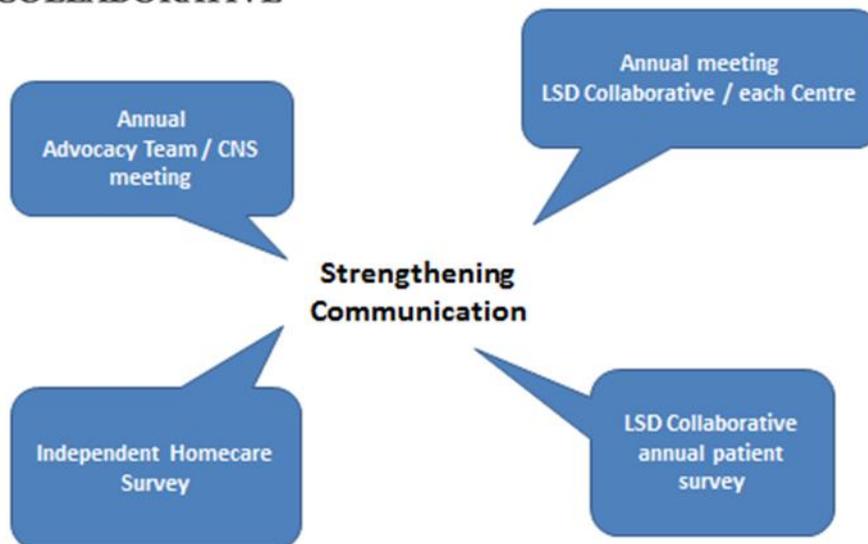
encouraging them to think outside the box and shortening the path to diagnosis. This in turn will enable the patient to be given appropriate clinical care at the earliest opportunity.

In March 2015 through several unrestricted educational grants from four Pharmaceuticals Companies an Educational Coordinator was appointed for 15 hours a week to manage the S4RD project working alongside the S4RD Committee and the LSD Collaborative. This post is housed at MPS House in Amersham and lined managed by the Association's Chief Executive on behalf of the LSD Collaborative.

### **Annual LSD Centre Clinical Audit Meeting**

This annual highly specialised service clinical outcome collaborative Audit workshop took place at Salford Hospital in November 2015 with all of the adult and paediatric LSD centres in England. At this meeting for the first time the UK LSD Patient Collaborative had a slot on the agenda and we fed back to the centres on patient feedback and opportunities to work more closely in the future, as summarised below;

**LSD** PATIENT  
COLLABORATIVE



### **Meeting with LSD Centres**

As part of the LSD Collaborative committeeman to strengthen communication with the LSD centre, see above, the Collaborative met with two of the centres in London in early 2016 and have meetings scheduled with all the other centres before the next clinical audit meeting in late 2016 and will report on the outcome of these meetings.

## **NHS Consultation on Specialised Services**

In April NHS England launched a consultation on developing a method to assist NHS England in making investment decisions in Specialised Services. The Association made a formal submission to the consultation document on behalf of the UK Gauchers community.

## **Research**

### **General**

The Association has given several small grants to several research projects over the past few years. These projects have carried out important research and in most cases have gone on to use the results to lever additional funds or identify further areas of research that need to be taken forward. In addition to giving grants, members of the Association support others as a stakeholder in collaborative grant applications through time and links with patients and their families.

### **GAUCHERITE**

Through our Board member Jeremy Manuel, the Association continues to be a partner, along with the eight specialist LSD centres in the UK in the '*Gaucherite*' project.

The project will examine at least 85 per cent of all UK Gaucher patients and 'stratify' them by the nature of their disease to allow therapy interventions to be targeted more effectively. They will also work closely with major industrial partners and The Gauchers Association. In 2015/16 the Association worked closely with the leading clinical team at Addenbrooke's Hospital on recruiting the targeted 250 Gaucher patients to this project through our newsletter and a You Tube video.

### ***Three Year PhD Impact Studentship***

In 2014 the Gauchers Association in partnership with Ahad Rahim from University College London (UCL) successfully applied for an Impact Studentship Award to continue the work that Ahad Rahim and Simon Waddington have been carrying out on Gene Therapy for Neuronopathic Gaucher Disease (nGD). The application is for a three-year PhD post. The Association in partnership with the Javon Trust awarded a grant of £32,535 for the project, with the remainder of the funding being provided by UCL. The PhD studentship was awarded to Miss Giulia Massaro, who recently joined Dr Rahim's laboratory and will be working in close collaboration with Dr Waddington's group. This studentship will investigate the viral vector administered to the mice via a minimally invasive intravenous route with two fundamental questions requiring answers:

1. Is this minimally invasive route of administration as effective in extending the lifespan of these mice and is the brain rescued from the lethal neurodegeneration?
2. Given the systemic nature of delivery, does this also address the visceral symptoms?

The Gauchers Association through its Neuronopathic fund also pledged to award £5,000 per year for the 3-year period towards the up keep of the mice colony that are vital to this research.

## ***Orphan Drug Application for Gene Therapy for the treatment of Gaucher Disease***

Following the positive results of the work of Simon Waddington and Ahad Rahim on the Intracerebral injections of nGD mice, the Association in partnership with Simon Waddington and Ahad Rahim and with the assistance of Dr Elin-Haf Davies applied for Orphan designation for Gaucher disease. On February 12<sup>th</sup> 2015 the Committee for Orphan Medicinal Products (COMP) at the European Medicines Agency (EMA) granted the Association, as the sponsor, a positive opinion for orphan designation (EMA/OD/303/14) for adeno-associated viral vector serotype 9 containing the human glucocerebrosidase gene (Gene Therapy) as a new potential treatment for Gaucher disease.

Since the Association received orphan designation in early 2015 the project team consisting of members of the Association, researchers' Dr Ahad Rahim and Dr Simon Waddington and their team at University College London (UCL) and Elin haf Davies as an independent Consultant have been in discussions with various Pharmaceutical Companies to explore possible avenues to take this work into a clinical trial with the Patient Organisation as a partner. In a commitment to keeping our members up to date, a session was held at the 7<sup>th</sup> nGD family conference on Sunday 15<sup>th</sup> November where our nGD patients and families were provided with an update on the clinical work and were able to ask the researchers questions.

### ***RAPSODI - Gaucher families helping find a cure for Parkinson's***

The Association continues to support the research being undertaken at the Royal Free Hospital into the link between Gaucher disease and Parkinson's by encouraging patients and their families to support the study through our newsletters and direct mailings. Tanya Collin-Histed has been working with the team at the Royal Free on the development of the online portal which will be the main tool that captures all the patient data, including working for the site and a video on how to use the portal.

### **Susan Lewis Memorial Fund**

Susan Lewis was a founder of both the UK Gauchers Association and the EGA. Following her death in 2007 the Gauchers Association established the Susan Lewis Memorial Award to provide grants and bursaries to doctors and other healthcare professionals from developing countries (particularly Eastern Europe) to allow them to travel to the UK Centres of Excellence to undertake mentoring and educational programmes in the treatment and management of Gaucher Disease.

A number of awards were made in 2015 and 2016, these included;

Through the fund the Association supported Dr Aimee Donald to travel to Sweden to visit Gaucher centres in Sweden and to present a poster at the WORLD conference in San Diego in February 2016.

All recipients of a Susan Lewis Memorial Award are required to write a piece for our bi annual newsletter to inform our members why they attended the meeting, what they learnt and how that can be translated back in the UK for patients and their families with Gaucher disease and other lysosomal storage disorders.

## **Treatment**

Gaucher patients continue to receive treatment paid for by the National Health Service. The cost of treatment remains high and with the development of treatments for other Lysosomal Storage Disorders we remain vigilant that all patients continue to receive the necessary drug as prescribed to them (see National Highly Specialised LSD Service Report)

## **New Treatments for Gaucher disease**

**Orphazyme** - See report under Neuronopathic Gaucher Disease on page 4

## **Eliglustat**

Genzyme's small molecule, Eliglustat for Type I adult patients received European marketing approval by the European Medicines Agency (EMA) in February 2015. The National Institute for Care and Excellence (NICE) commenced a formal appraisal of the new treatment under the new NICE Highly Specialised Technology appraisal process in 2014. The Association was involved in the initial scoping exercise of this treatment in January 2014 and undertook an in-depth patient survey to support our patient evidence for the NICE appraisal. In late October 2014 Genzyme made the decision to put the appraisal on hold whilst they continue to develop their pricing model for Eliglustat in the UK which will ensure that patients are able to be prescribed a treatment based on their clinical needs rather than based on cost. The process was recommenced in 2016 and the first appraisal meeting is scheduled for September 2016. As part of this process the Association has identified two patient experts with experience of taking an oral treatment for their Gaucher disease. These two patient experts will work closely with the Association's Chief Executive to present evidence as part of the appraisal process.

**Genzyme's small molecule for Type III Gaucher disease** – see report above

**Gene Therapy for Gaucher disease** – see report above

The Association maintains regular contact with all pharmaceutical companies involved with Gaucher disease and researchers to ensure that members are kept up to date with all developments and we relay to the companies the concerns and expectations of members.

## **Managing Information and Communication**

The Association continues to supply up-to-date information on the telephone, by mail and through our website. Our six-monthly newsletter is sent out to families, doctors and other interested parties worldwide, and our extensive website is read all over the world.

## ***International Gaucher Day 2015***

The UK Gauchers Association joined many Associations' around the world to celebrate International Gaucher Day (IGD) on 1<sup>st</sup> October 2015. IGD is the brainchild of the European

Gaucher Alliance (EGA). The aim of IGD is to raise international awareness of Gaucher Disease and the slogan for the day is 'Rare but Not Alone.'

In the UK, the Association asked our members to celebrate IGD by organising their own events either at home or work with friends, family, and colleagues. To help our members celebrate this day we sent them materials branded with the new IGD logo, all to help raise awareness.

### **Rare Disease Day 2016**

To celebrate Rare Disease Day the Association ran a Facebook campaign using stories from our Members and facts about Gauchers Disease.

### **Database**

The Association operates a Members database which was last updated through a member mail out in 2014.

### **Website**

The Association's site is updated regularly. The site allows regular e-mail alerts to our members to ensure they are kept up to date with the latest news in the Gaucher field. Our online newsletter is now sent to over 450 people worldwide.

### **Facebook**

The Association posts news every Friday on new projects, research updates, current political issues etc. and has 517 followers.