

International Gaucher Alliance's Strategic Plan 2021 - 2023

(amended version of the strategic plan 2019 - 2023)



The IGA's Strategic imperatives seek to achieve a **strong voice** for Gaucher patients through collaboration and partnership.

- **improve** Gaucher patients' **access** to optimal diagnosis, treatment and care
- **influence** the Gaucher **research agenda** so that it's focused on addressing key unmet needs
- **support member organisations** to be more effective and sustainable

www.gaucheralliance.org

September 2020

Strategic imperative 1: Improve Gaucher patients' access to optimal diagnosis, treatment and care

<i>Short term goals and tactics</i>	<i>Long term goals and tactics</i>
<p>By the end of 2021 we will have put the structures in place that will enable us to influence healthcare policy at a global level.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Develop a comprehensive profile of the global Gaucher patient challenges using our Members 2021 country reports and input from our regional manager network. • Support our members with information and best practices to work together with other rare disease organizations in their countries with a goal of the development and implementation of rare disease plans in their countries. • To share links of websites with information about rare disease plans (EUROPLAN, EURORDIS etc.) in newsletters, social media and our web page. 	<p>By the end of 2023 we will have established Gaucher disease as a European, global and national public health priority.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Have an established dedicated IGA session at EWGGD. • Use membership of RDI to influence the work of the United Nations Committee for Rare Diseases and World Health Organisation's agenda relating to rare diseases and ensure that RDI gives sufficient visibility to Gaucher disease by attending meetings and contributing to development of policy positions. • Ensure resources so that IGA can be effective in influencing and contributing towards: <ul style="list-style-type: none"> - EU/International policy - Pharmaceutical industry work programs - Clinical research - Active participation in current networks of patient organizations and health professionals (Rare diseases, Metabolic diseases/ Gaucher disease) - Identification of other opportunities.
<p>By the end of 2021 we will have started to develop the infrastructure to improve the standards of clinical care available to Gaucher patients globally.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Work with other stakeholders to build a collaborative model for the education and support of doctors managing Gaucher patient that will include: <ul style="list-style-type: none"> - Developing consensus guidelines on the clinical management of Type 1 Gaucher disease patients 	<p>By the end of 2023 we will have improved the standards of clinical care of patients with Gaucher disease, with a specific focus on neuronopathic patients globally.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Work with other stakeholders to review and update the existing consensus guidelines on the clinical management of nGD patients. • Establish the IGA's Global Patient led nGD registry GARDIAN to include:

<ul style="list-style-type: none"> - Promote the value of current Gaucher registries including the Gaucher Outcome Survey (GOS) and International Collaboration on Gaucher Group (ICGG) and where possible identify possible collaboration to avoid the dilution of patient data. - Increase awareness of the correct diagnostic assessments through an instruction video on the IGA website, printed literature and piloting dedicated in country/regional masterclasses in country on-site clinics - Identify the unmet research needs of patients through our member organisations and the unanswered research questions and ensure these are communicated to the EWGGD, EHA, Industry, RDI, Eurordis, MetabERN, SSIEM, ICIEM and regulators. • Increase awareness of a funding opportunity for researchers and doctors interested in Gaucher disease to undergo continual professional development and collaboration through the UK Gaucher Association's Susan Lewis Memorial Fund. • Identify and promote preceptorship opportunities for new doctors in the field. • Establish with TF 2 a policy unit to identify and progress position papers /guidelines on aspects of clinical care, research and quality of life. 	<ul style="list-style-type: none"> - The development and validation of a nGD PRO and Observer reported outcomes - The use of digital technology to further understand the impact of the disease of patient's ability to function daily - The implementation of GARDIAN at clinical sites in line with the recommendations of the IGA nGD registry phase I feasibility study 2019. - To have implemented a pan sponsored registry that can provide the following functions: <ul style="list-style-type: none"> - Post marketing requirements - Control arms for clinical trials - Roll over recruitment from clinical trial patients. - To collaborate with other existing registries to identify interoperability opportunities to share data. • Improve the knowledge of the disease and increase awareness of the signs and symptoms through dedicated teaching clinics for neuronopathic Gaucher Disease (nGD) through the RM programmes. • Increase awareness of the correct diagnostic assessments through the promotion of the new published definition of nGD 2020. • Identify the unmet research needs of patients through our member organisation and the unanswered research questions and ensure these are communicated to the EWGGD, EHA, Industry, RDI, Eurordis, MetabERN and regulators. • Using the IGA website to provide information of all licensed treatments for Gaucher disease with a link to a search facility to published papers. • Encourage our members to Increase awareness of Gaucher Diseases amongst medical students through the cooperation with medical student bodies, providing expert doctors and patients for lectures, providing Gaucher disease information booklet.
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<p>By the end of 2021 we will have the structures in place to improve the timeliness of diagnosis of Gaucher disease.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Develop an online resource on the IGA website that identifies diagnostic centers for Gaucher disease globally. • Continuously use the platform of International Gaucher Day (IGD) to raise awareness about Gaucher disease among those health professionals who have an impact on patients and their disease journey. • Work with IGA members to review patient stories to identify a series of ‘key messages’ on important symptoms (red flags) that are potentially indicative of a diagnosis of Gaucher disease and publish the stories on the website. • Promote the awareness of the value of diagnostic platforms to clinicians and patients. 	<p>By the end of 2023 we will have reduced the number of patients globally who are diagnosed late with Gaucher disease.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Roll-out an awareness campaigns about diagnosis called “Gaucher red flags” in collaboration with: <ul style="list-style-type: none"> - Health professionals including those working in the field of hematology, metabolic, orthopedics, oncology... - Health professionals in general practice through supporting initiatives such as Mendelian and Saventic. - Cooperate with EWGGD, EHA, SSIEM, ICIEM and other organisations identified to ensure global coverage. - IGA Member organisations • Use membership of the European Haematology Association’s (EHA) European Gaucher Network (EGN) advisory working group to increase hematologists’ awareness of Gaucher Disease through inclusion in syllabus and education sessions at conferences. • As a member of Takeda’s Medical Expert Committee, ensure education and access to diagnostics is a key aspect of Takeda’s charitable access program. • Support and collaborate where possible with the work of FYMCA to increase education of doctors in the developing world and link with our regional manager programme particularly in Africa.
<p>By the end of 2021 we will have improved the mechanisms to understand the challenges that Gaucher patients’ face to access optimal treatment and care.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Ensure resources to be an active member of the MetabERN Patient Advisory Group by attending planning meetings and participating in relevant thematic committees. • Commission an independent organisation to conduct an analysis of the current models of charitable access to treatments for 	<p>By the end of 2023 we will have greatly improved Gaucher Patients’ access to optimal treatment and care globally.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Continuously analyze the situation in IGA non-member countries with the help of the regional managers, doctors, the pharmaceutical industry and other key stakeholders, to develop a plan for addressing the key gaps to improve diagnosis, the education of doctors and access to treatment.

<p>Gaucher disease and use the results of this work to develop a long-term strategy for how IGA will engage in charitable access programmes.</p> <ul style="list-style-type: none"> Using our members country reports and other sources of information to build a database of the countries where patients have limited or no access to reimbursement for Gaucher disease treatments and map the reimbursement systems to understand ways in which access challenges can be addressed in collaboration with other stakeholders. 	<ul style="list-style-type: none"> Together with our member organisations, regional managers and pharmaceutical industry, develop an online resource on our website that will identify clinical experts, treatment centers in both member and non-member countries. Promote and actively engage in the development of a new sustainable business model for charitable access programmes for Gaucher disease treatments. Target charitable access programmes in countries where there are diagnosed untreated patients. Put pressure on pharmaceutical companies to make available their products in all countries to ensure that patients have access to the widest choice of products. Agree on a clear position on Biosimilars and produce a position paper that will communicate this position to different stakeholders in conjunction with TF 2.
<p>By the end of 2021 we will have started to empower patients and their families through the provision of comprehensive information about all aspects of Gaucher disease.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> Ensure that we share up to date information about clinical trials in Gaucher disease and different aspects of the condition through all communication platforms. 	<p>By the end of 2023 we will have empowered Gaucher patients and families worldwide to understand what treatment and care they need to optimise their outcome.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> To reach as many patients and their families through making our information accessible by providing it in as many languages as possible cooperating and working together with our member organisations.
<p>By the end of 2021 we will have a better understanding of the impact of being diagnosed with a comorbidity e.g. Parkinson’s Disease (PD), Multiple Myeloma on families within the Gaucher community.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> Undertake a piece of research within our patient community on the impact of having Gaucher disease and Parkinson’s disease or 	<p>By the end of 2023 we will have put into place a structure to support Gaucher families affected by comorbidities e.g. Parkinson’s disease (PD), Multiple Myeloma.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> Providing a dedicated area on our web page for information on comorbidities including:

<p>a family member with the Glucocerebrosidase (GBA) mutation developing Parkinson’s disease, to understand their clinical needs, quality of life issues and the role the IGA could play in fulfilling supporting them.</p> <ul style="list-style-type: none"> • In conjunction with TF 3 hosts a PD/GD webinar for members to increase awareness and improve knowledge of this area of need. 	<ul style="list-style-type: none"> - all aspects of Parkinson’s Disease including research and drug development specific to Gaucher Disease and PD and linking up with PD related charities to tap into their knowledge and resources regarding living with PD and practical information - cancer i.e. multiple myeloma, bone including links to published papers, research and related sources for information and practical support <ul style="list-style-type: none"> • To work in conjunction with TF 2 to identify doctors, researchers and other persons that have an interest in GD/PD mutations to ensure there is a scientific forum on GD/PD.
<p>By the end of 2021 we will have a better understanding of the clinical and non-medical needs of our older Gaucher patient community.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Develop a questionnaire on issues and needs of older Gaucher patients • Support our member organisations to undertake a piece of research within their patient community to understand their clinical needs and quality of life issues. 	<p>By the end of 2023 we will have improved the lives of our older Gaucher community.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Use the results of the research to implement programmes and services to meet their unmet needs and identify how the IGA could support them. • To publish the findings of the research to raise awareness and provide evidence for our member organisations to appropriate access resources.

Strategic imperative 2: Influence the Gaucher research agenda so that it's focused on addressing key unmet needs from a patient perspective	
<i>Short term goals and tactics</i>	<i>Long term goals and tactics</i>
<p>By the end of 2021 we will continue with our efforts to influence the Gaucher disease research agenda.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Facilitate a multi stakeholder meeting to identify the unmet clinical and quality of life needs of patients, the unanswered research questions, and agree a robust action plan. • Work with relevant stakeholders to be involved in current and future development of Gaucher-specific patient reported outcome measures for GD 1 that can be used in clinical trials. • Establish a Scientific Advisory Committee to guide the IGA's thinking in relation to research in cooperation with the EWGGD and other global experts to ensure Global representation. • Ensure that current research being undertaken in the areas of co-morbidities e.g. Parkinson's Disease, bone disease, and cancers in relation to Gaucher disease is integral on the agenda for all research meetings. To undertake in conjunction with TF 1. • Establish with TF 1 a policy unit to identify and progress position papers /guidelines on aspects of clinical care, research and quality of life. 	<p>By the end of 2023 we will be a key driver of research in the Gaucher disease setting.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • To ensure that we continuously provide different mechanisms for IGA Members to provide feedback on proposed research and areas of unmet need. • Supporting and cooperating with EWGGD as a global platform for different stakeholders to meet and create a more strategic approach to advancing scientific research of Gaucher disease. • Work in collaboration with the EWGGD to implement a programme of activities between the two-year scientific meeting to advance research, information, and education in Gaucher disease. • Promote the use of validated, Gaucher-specific patient reported outcome measures in clinical trials. • Encourage, support and work with researchers in their search for a cure for Gaucher disease. • To work in conjunction with TF 1 to identify doctors, researchers and other persons that have an interest in GD/PD mutations to ensure there is a scientific forum on GD/PD.
<p>By the end of 2021 we will have begun to secure a patient voice in the development and regulation of medicines for Gaucher disease.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Position the IGA as 'the go to' body to provide patient input into medicines development for Gaucher disease. 	<p>By the end of 2023 we will have firmly embedded the patient voice embedded in the research and development of new medicines for Gaucher disease.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Continue to engage at a high level with pharmaceutical company's executives to ensure that company trials are focused on the greatest unmet needs.

<ul style="list-style-type: none"> • Push for regular meetings with the leaders of companies developing medicines for Gaucher. • Facilitate recruitment of patients into industry trials that IGA believe are patient friendly and focused on patient need (e.g. identifying naïve patients). • Work with pharmaceutical companies to address current challenges with Gaucher registries and explore how a more collaborative approach could aid better data collection. • Ensuring we position ourselves to be involved in any study using the repurposed drug Ambroxol to address unmet treatment needs for Gaucher patients. • To publish a report on the global Gaucher community’s opinion of Gene Therapy for GD 1. 	<ul style="list-style-type: none"> • Provide patient input early into all trials that pharmaceutical companies are conducting in the Gaucher disease setting. • Support a clinical study of Ambroxol in GD1 and GD 3 patients, taking it through the medicines development pathway to bring it to patients at a cost sustainable to patients in LIMC.
<p>By the end of 2021 we will have started to build our capacity to generate patient evidence.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Through GARDIAN, start to generate with the SAC of IGL to publish evidence on nGD to understand the burden of the condition, using clinical data and PRO / ObsRO. 	<p>By the end of 2023 we will be a key stakeholder in generating evidence on the lived experience of Gaucher disease.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Maintain and improve a systematic approach, through the nGD registry GARDIAN to gathering evidence from patients and families on different aspects of living with nGD and use this evidence to drive further research and show the value of potential new therapies.
<p>By the end of 2021 we will have established an easy to understand listing of clinical trials for Gaucher disease.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Create an area on the IGA website where on-going clinical trials on GD are listed and updated on a regular basis. 	<p>By the end of 2023 the IGA website will be the “go to” resource for patients and families looking for information about research on Gaucher disease.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Start to provide easy-to-understand summaries of the results of research in Gaucher disease. • Push for the early translation of research findings into clinical practice.

<p>By the end of 2021 we will have started to build our capacity to drive the Gaucher research agenda.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Identify patient advocates who already have expertise in research or who would like to build their expertise and provide support for them to learn more about the drug development process. • To work in conjunction with TF 4 and GWG programme on this. 	<p>By the end of 2023 we will have built a pool of Gaucher patient research experts who can represent the patient community on research committees.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Continue to build the pool of patient research experts and provide them with opportunities for ongoing training. • Secure positions for IGA's expert patients on key committees and ensure that patients have a voice in regulatory decision making i.e. (European Medicines Agency (EMA) and Health Technology Appraisal (HTA's)).
<p>By the end of 2021 we will have established the IGA as the 'go to' Gaucher organisation by the Pharmaceutical Industry for medicines development and patient support programmes.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Push for a commitment from each of the pharmaceutical companies involved in Gaucher disease to hold an annual meeting between IGA leaders and their senior leadership teams. • Seek to have a Gaucher patient expert on every Gaucher related advisory board/project and ensure that IGA representatives have the knowledge and skills needed to best represent the Gaucher patient community perspective. 	<p>By the end of 2023 we will have established the IGA as the global patient voice for Gaucher disease with the pharmaceutical industry, researchers, and key opinion leaders.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Show leadership by convening regular multi-stakeholder roundtable meetings on how to address the big challenges facing Gaucher patients. • Increase the number of published poster presentations and articles from IGA, by improving the communication of IGA board members and regional managers with member organizations and non-member countries, to show that the IGA is the cornerstone of the Global patient community with unique access to understanding the Gaucher community (patients, families, health professionals etc.), the needs, challenges, problems and the possible solutions in going forward.

Strategic imperative 3: Support member organisations to be more effective and sustainable

<i>Short term goals and tactics</i>	<i>Long term goals and tactics</i>
<p>By the end of 2021 we will have a better understanding of the training needs of our member organisations.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Undertake evaluation of how we have supported our members and find new approaches to encourage and support our member organisations. • Explore external training opportunities that can be recommended to members. • To help members to adopt a code of conduct appropriate to their national regulatory obligations and/or organisational set-up, to make this mandatory within a 12-month period of becoming a member. • Identify policies and organisational documents that could be useful for members, including help with financial matters • Support training of member organizations with a programme of webinars on subjects already defined from a need assessment. 	<p>By the end of 2023 we will have established a system for building capacities of our member national patient organisations and their ability to support the needs of their patient communities.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Conduct regular webinars on topics of interest to members. • Make members aware of external training opportunities. • Facilitate best practice sharing between members at face to face meetings and online. • Provide templates for policies and other useful organisational documents through a toolkit. • Conduct evaluation of the system for capacity building. • Regularly review topics of interest to our members.
<p>By the end of 2021 we will have a clear vision of the future development of the Go with Gaucher programme.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Undertaking a review of the Go with Gaucher (GwG) programme to ensure it meets the needs of members and underpins the IGA’s strategic imperatives. • Using the results of the review of the GwG programme, implement the findings to shape the programme accordingly. • Implement a GWG program with new young people. 	<p>By the end of 2023 we will have actively secured the future voice of the Gaucher patients by ensuring succession planning.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Using the Biennial GwG event to identify those young adults that could contribute to the IGA work programme. • Co-opting new people in the board that can bring key skills to the Board that are currently not present. • Using the GwG project to recruit future Regional Managers from the pool of young adult Gaucher patients.

<ul style="list-style-type: none"> • Use webinars with old and new GWG people to improve communication, follow up... 	<ul style="list-style-type: none"> • Developing a peer to peer mentoring programme using our more experienced patient leaders to support younger patient leaders e.g. attending Lysosomal Disease Network WORLD Symposium, Eurordis, SSIEM (Society for the study of inborn errors of metabolism) meetings.
<p>By the end of 2021 we will have understood what structures needs to be put in place for the IGA to be a truly global organization.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Undertake review and evaluation of RM network with the RMs and see how to go forward and how they can support each other and be stronger and connected, and plan future steps. • Implement regional workshops into the programme at the IGA biennial member’s meetings to develop and create stronger regional activities. 	<p>By the end of 2023 we will ensure that every patient has access to an appropriate support network, wherever they live in the world.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Continue to develop a network of regional structures globally to increase the footprint of the IGA as an efficient, effective business model that is able to support patients, carers, and clinicians.
<p>By the end of 2021 we will have identified the most effective ways to communicate with our members.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Develop a communications strategy that will underpin all aspects of when and how we communicate with our Members through different information platforms available. • Publish a ‘What being a member of the IGA can do for you’ statement to all our members and potential members. • Provide members with the opportunity to meet Board members/CEO during the EWGGD Biennial meeting to seek advice and discuss national matters through our “surgery” program. • Translate the main documents of the IGA into Spanish, including the country report. 	<p>By the end of 2023 we will have developed, strengthened and supported our members.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Provide members with the opportunity to attend meetings (e.g. member’s biennial meetings, regional meetings, to be the patient voice at Gaucher meetings). • Encourage members to contribute to the IGA newsletter and share successes. • Provide members with opportunities to be involved in the IGA i.e. IGA Board member, GwG, Regional Manager, volunteers in work streams. • Provide members with regular opportunities to speak with board members/CEO either face to face or using Zoom. • Support the development of regional patient meetings.

	<ul style="list-style-type: none"> • Provide information on independent funding opportunities and guidance and advice on how to utilise voluntary support as a source of income. • Translate main documents into two further languages following research into what would be the most useful.
<p>By the end of 2021 we will have a clearer understanding of the future resources we need to service the needs of our members and the non-member community.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Establish a dedicated role in the IGA staff team to support our existing members and non-member organisations. • Evaluate the documents ‘board members responsibilities as a contact person for member countries’. 	<p>By the end of 2023 we will have a dedicated resource to support new and fledging patient groups.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Provide a service to patients/patient advocates of new and fledging groups to undertake due diligence to identify an action plan that outlines the different tasks that need to be undertaken, the resources needed and an agreed timeline. • Developing a tool kit for new patient organizations. • Increase our membership to 65 countries and to have representation from each region of the globe.
<p>By the end of 2021 we will have started to build the capacities of the IGA membership to be powerful at a national level.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Start to build a one-stop resource on our web page for members listing training opportunities/programmes; best practice documents and guidelines. This is an ongoing activity that uses the IGA web site, newsletters and social media. • Develop a volunteer program for the IGA to up-skill volunteers and in that way support national organizations. • Work together with Task force 4 to successfully implement town hall meetings and provide training at board meetings. 	<p>By the end of 2023 we will have built a strong network of Gaucher Patient organisations that is capable of taking action at a local and national level to address problems faced by Gaucher patients and their families.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Expand the online portal to ensure that it contains as many resources as possible and provides opportunities for sharing of best practice. • Provide members with the opportunity to attend meetings (e.g. members’ biennial meetings, regional meetings, the patient voice at Gaucher meetings). • Provide members with opportunities to be involved in the IGA i.e. IGA Board member, GwG, Regional Manager, volunteer on a work stream.

	<ul style="list-style-type: none"> • Provide members with regular opportunities to speak with board members/CEO either face to face or using Zoom. • Support the development of regional patient meetings.
<p>By the end of 2021 we will have increased support to patients, their families and healthcare professionals in countries currently not involved with the IGA.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Continue to support the RM network with strengthening of RMs through training, webinars and face to face meetings. • Have one board member dedicated to communicatecommunicating and manage RMs. • Continue to increase the RM network – identify new areas and new RM volunteers to expand the RM program. • Develop specific volunteer program for Regional managers. • Establish procedure to fill information about RM countries that are not IGA members into the IGA database. 	<p>By the end of 2023 we will have an established a regional global structure.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Utilisation of the outcome of the Regional manager program to establish the best approach and increase the footprint of the IGA as an efficient, effective business model that can support patients, carers, and clinicians. • Supporting the establishment of new patient organizations in countries included in the RM program. • Improving education of doctors and with that implementing clinical guidelines, having established centres for Gaucher. • Increasing awareness about GD among health professionals and government institutions. • Education of families and patients to support them in advocacy. • Developing and maintaining communication and cooperation with health professionals, patients, families, pharmaceutical representatives and others to exchange information and knowledge and provide advice on improvement of quality of life of families with GD.
<p>By the end of 2021 we will have a better understanding of how to make International Gaucher Day (IGD) more accessible to our members.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Re-shape the aims of IGD with our membership. 	<p>By the end of 2023 International Gaucher Day (IGD) will be a globally recognised event that is effectively deployed by our members to raise awareness of the challenges the Gaucher community face at a national level.</p> <p>To be achieved by:</p> <ul style="list-style-type: none"> • Put a process in place for our board members and members to collectively decide the annual theme and creative concept for

<ul style="list-style-type: none"> • Undertake a survey of members to define the current barriers they face in participating in IGD and identify what resources they would need to participate in future IGD. • Conduct an analysis of positive experiences in raising global awareness of other rare conditions and consider applying successful techniques to IGD. • At the members biennial meeting host a workshop on IGA and from this develop a plan of action for addressing barriers and securing necessary resources for increasing the reach and impact. 	<p>International Gaucher Day which will reflect both the ongoing challenges and things to celebrate associated with Gaucher disease.</p> <ul style="list-style-type: none"> • Provide a toolkit for members that contains the resources they need to conduct an IGD event. • Hold a webinar for members prior to IGD to enable them ask questions and share ideas for IGD events. • Establish IGD on the World Health Organisation (WHO) calendar of events and share with Eurordis, RDI and other relevant European/global rare disease platforms/forums. • Use the website more extensively to communicate the scope and impact of IGD events.
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