The mission of the Dystonia Medical Research Foundation (DMRF) is to advance research for more effective treatments and a cure, to promote awareness and education, and to support the well-being of affected individuals and families.

The DMRF will focus on the following priorities in 2015 in support of the Foundation’s mission.

**RESEARCH**

To achieve its ultimate mission of finding a cure for all forms of dystonia, the DMRF will support scientific investigations through its Research Programs. In doing so, DMRF will: attract new investigators in the field, support innovative research that will lead to better understanding of the mechanisms of the dystonias and identification and characterization of therapeutic targets; facilitate the development of more effective agents and devices for the dystonias in the next decade.

**RES Objective 1:** Identify, stimulate, support and monitor cutting-edge research aimed at expanding the knowledge of the genetic, molecular, physiologic and pathologic basis of dystonia.

**Action Steps:**

1. MSAC and identified outside experts invited to annual meeting to review recent research progress and provide recommendations to Science Committee/Board of Directors for pursuing the most critical areas of research and new directions;

2. Review new and renewing grants and fellowships and recommend funding to Science Committee/Board of Directors;
3. Monitor grants funded under the Myoclonus Dystonia Research Program and all other approved research grants;
4. Develop scope and criteria for and fund a Mahlon R. DeLong Young Investigator Award;
5. Develop scope and criteria for and fund “Concept” Awards, pending availability of funds;
6. Release RFA on torsin/nuclear envelope biology in the fall 2015;
7. Work with the NINDS staff on new approaches and strategies of working together;
8. DMRF Chief Scientific Officer to serve as a reviewer for Dystonia Coalition Pilot Project and Career Development Award Program applications pending approval of renewal funding for Dystonia Coalition;
9. DMRF Chief Scientific Officer to represent DMRFC whenever scientific assessment, advice or reviews are needed.

RES Objective 2: Support the development of knowledge, tools, resources and mechanisms to share information to promote and advance worldwide dystonia research.

Action Steps:
1. Promote to the research community funding and collaboration programs and initiatives at DMRF, Dystonia Coalition, NIH and other dystonia research funding sources;
2. Continue implementing brain banking plan for increased donor registrations and investigational use of tissue samples and continue to work with the Dystonia Brain Collective to engage other dystonia patient organizations to support the operation of the private dystonia collection at the Harvard Brain Tissue Resource Center;
3. Identify new opportunities for modern neuropathological studies of dystonia brains;
4. Participate in, promote enrollment in, and provide support for the Dystonia International Patient Registry (DiPR) coordinated by Tyler’s Hope;
5. Support the operations of the Global Dystonia Registry;
6. Maintain communication and explore collaboration opportunities with European dystonia organizations and research groups;
7. Provide current updates and report on research news on the DMRF website and other DMRF publications.

RES Objective 3: Establish contracts with academic researchers or pharma/biotech companies to conduct specific translational research or development projects with the immediate goal to discover and validate druggable targets

Action Steps:
1. Monitor ongoing contract progress to agreed milestones; review reports, provide feedback, hold meetings, if necessary;
2. Conclude the major phase of Project FireSky; analyze and publish the data; and
3. Assess unique opportunities for new contracts with translational or clinical potential that will be presented to the Science Committee for consideration.
RES Objective 4: Serve as the administrative center for the Dystonia Coalition, a clinical research network (collaboration of medical researchers and patient advocacy groups) sponsored by the NINDS and the Office of Rare Diseases (ORD) to advance the pace of clinical and translational research in the dystonias to find better treatments and a cure.

Action Steps:

1. Provide payments to clinical centers contributing to the Dystonia Coalition in proportion to their recruitment efforts for various studies being conducted;
2. Monitor clinical research subcontract agreements with sites participating in Dystonia Coalition Project 2;
3. Provide logistical and planning support for the Dystonia Coalition’s annual meeting, including payment of all approved expenses;
4. Provide payments to international consultants involved with the Coalition;
5. Disburse award payments to recipients of the Coalition’s Career Development and Pilot Project Awards Programs;
6. Manage the funds received from Emory University (budgeted for bridge period of the DMRF subcontract) to pay out project related expenses outlined above;
7. Manage the private funds contributed by other dystonia patient organizations to support key Coalition projects/activities;
8. Provide access to DMRF’s conference call system to hold conference calls as needed;
9. Participate in monthly Executive Committee calls and administrative calls to ensure smooth operations of all Coalition activities;
10. Prepare for the procedural and operational changes required to serve as the administrative center should the Dystonia Coalition funding be renewed.

RES Objective 5: Interact with the pharmaceutical/biotech companies and other potential partners in the research and development of dystonia therapies.

Action Steps:

1. Continue to identify, engage and interact with pharmaceutical and medical devices companies that have potential or expressed interest in dystonia therapeutics development;
2. Present dystonia as a drug/devices development and market opportunity;
3. Attend the American Academy of Neurology and Society for Neuroscience Annual Meetings and other meetings to introduce dystonia and DMRF to potential commercial partners;
4. Work in partnership with the Dystonia Study Group and Eisai to administer funds to sites participating in the Cervical Dystonia clinical trial;
5. Collaborate with Addex to advance the development of dipraglurant, a novel drug targeting metabotropic glutamate receptor 5, for dystonia, including designing a development plan for dipraglurant, protocols, budget, regulatory path and detailed scientific rationale for the indication.

RES Objective 6: Host and attend meetings to address current scientific/therapeutic issues, facilitate information sharing, network building or identification of critical research areas and future directions.
Action Steps:
1. Attend local support group or other educational meetings when schedules permit;
2. Organize educational webinars for the dystonia community;
3. Provide financial support for and attend “5th Biennial Workshop on Dystonia” in Rome, May 2015;
4. Attend/provide support for other dystonia-related meetings, when appropriate;
5. Organize a Clinical Fellowship dinner meeting in conjunction with AAN Annual meeting in Washington, DC;
6. Organize a follow up meeting on Myoclonus Dystonia in Fall, pending availability of funding;
7. Work with Parkinson’s Disease Foundation and Columbia University to organize and host a symposium and dinner honoring Stan Fahn in New York City in April;
8. Assess readiness for 6th International Dystonia Symposium; and
9. Executive Director to serve on NINDS Council and attend all meetings.

RES Objective 7: Improve the clinical treatment for those affected by dystonia through the implementation of a clinical fellowship program to facilitate the training of clinicians and young investigators in dystonia research.

Action Steps:
1. Secure financial support for the DMRF Clinical Fellowship Program;
2. Work with the Clinical Fellowship Review Committee to oversee the program’s objectives, application procedures and then evaluate 2015 program – when the RFA should be released, deadlines, etc.;
3. Promote the program within the movement disorders clinical community;
4. Make site visits to fellows as travels/schedules allow.

AWARENESS & EDUCATION

The DMRF supports awareness and education programs and activities to decrease the number of misdiagnosed persons, improve the quality of life of affected persons and support the Foundation's fund development efforts. In 2015, the DMRF will build on the successes of 2014 and work to increase awareness and understanding of dystonia and of the Foundation with the general public, the healthcare community and affected persons and their families.

A&E Objective 1: Communicate relevant, accurate dystonia and Foundation news through the production of three issues of The Dystonia Dialogue, scientific updates through the Promise & Progress and the 2014 Annual Report.

Action Steps:
1. Working with the editorial board, identify key topics for each issue of the Dialogue;
2. Develop, implement and comply with a 2015 Dialogue production schedule that complements the DMRF’s development efforts with issues distributed March 1, June 15 and October 26;
3. Place on-line versions of stories and publications following each printing;
4. Working with program staff to develop copy for the 2014 Annual Report to be available by May 1, 2015;
5. Working with the development team, develop a plan to promote network events and materials;
6. Working with science team, develop a lay summary of DMRF research efforts for the Promise & Progress report to be distributed by April 1, 2015.

A&E Objective 2: Maintain a cutting-edge website that supports all DMRF priorities.

Action Steps:
1. Working with Masuga Design, the selected vendor, develop and monitor the timeline for refinements to the DMRF website needed to optimize utilization.
2. Update the website on an as needed basis to keep content current and easily accessible;
3. Post webinar recordings to extend educational outreach;
4. Track web traffic and trends.

A&E Objective 3: Conduct community and web-based educational forums.

Action Steps:
1. Identify at least 4 markets and develop and implement plans for each program – work with development to get programs underwritten and evaluate each session;
2. Explore feasibility of possible family symposium in 2016;
3. Identify topics for 2-3 webinars (topics to be determined), promote availability of sessions;
4. Work with support groups to assist in their educational programming.

A & E Objective 4: Promote dystonia awareness by engaging the DMRF community and the news media.

Action Steps:
1. Working with the Awareness & Education Committee, explore how the internet and social networks can be better utilized to raise dystonia awareness;
2. Assess the need for a policy to guide management of these networks – nationally and each DMRF support group operated site;
3. Maintain a pipeline for regular production and distribution of coordinated communications on DMRF events and news, including press releases, website announcements, texts, and use of social media;
4. Conduct “Dystonia Moves Me” campaign to take place in September 2015 during Dystonia Awareness Month. Announcement to support network and community in March 2015.
5. Collaborate with other Dystonia PAGs to have September recognized as Dystonia Awareness Month in all 50 States by July 1, 2015.
A & E Objective 5: Maintain and promote scientifically and organizationally accurate resource materials that meet the needs of the community.

Action Steps:
1. Review of resource materials, print and electronic (video/audio);
2. Develop and implement a schedule for revising the identified materials;
3. Coordinate the dissemination of dystonia news through e-news; social networking sites, website, announcements and press releases (when relevant).

ADVOCACY

The DMRF will work to improve the lives of those affected by dystonia through an increased awareness of elected officials of dystonia and the policy needs of the dystonia community.

Ad Objective 1: Develop and implement a legislative agenda that meets the needs of the dystonia community.

Action Steps:
1. By January 30, 2015 work with Health & Medicine Counsel of Washington (HMCW) and the other Dystonia Advocacy Network (DAN) member organizations, to finalize the 2015 legislative agenda and agenda for Advocacy Day. Monitor progress throughout the year toward achieving the 2015 legislative agenda;
2. Develop and implement plans for Advocacy Day, April 14-15, in Washington, DC;
3. Recruit advocates to participate in Advocacy Day from key legislative districts as identified by HMCW and distributed to DAN member organizations by January 30, 2015;
4. Announce the Douglas Kramer Young Advocate award applications by February 1, 2015 and evaluate applications and determine awardee by March 15;
5. Maintain a legislatively up-to-date DAN website that also allows for advocate recruitment;
6. Develop and implement a communication plan for dystonia advocates;
7. Assess the need for State legislative programs to address patient access concerns as needed in 2015;
8. Partner with other organizations, as identified by issues, support mutual legislative efforts.

Ad Objective 2: Maintain listing of dystonia on the Congressionally Directed Medical Research Program managed by the Department of Defense.

Action Steps:
1. Identify Congressional champions for DoD funding and a strategy to engage them;
2. Include this issue on the DAN legislative agenda;
3. Identify veterans who are willing to work on this issue and assist efforts;
4. Working with HMCW team develop a program for visits in key Senate offices during the August recess by advocates on this topic;
5. Implement plans for a letter writing campaign on DoD dystonia research funding;
6. Identify a person(s) willing to serve as consumer reviewers for the DOD application review panel and complete application(s).

Ad Objective 3: Ensure access to all FDA approved treatments for dystonia.

Action Steps:
1. Identify key States and develop a plan to educate the major carriers and Medicare/Medicaid in those States regarding dystonia and its treatments, including but not limited to working with State Insurance Commissioners, Medicare Regional Medical Directors and others who might be helpful with this issue;
2. Look for opportunities to partner with the clinical and pharmaceutical communities on implementing the plan;
3. Investigate the benefits for dystonia treatment offered through the State exchanges and develop a plan to address those that may present challenges for treatment;
4. Provide information to the dystonia patient community on the pharma sponsored patient assistance programs.

SUPPORT

The DMRF will work to improve the quality of life for dystonia-affected persons and their families.

S Objective 1: Provide support resources for all affected persons/families.

Action Steps:
1. Through the Support Committee, assess and monitor support needs and the programs designed to address these needs;
2. Conduct survey to all support Leaders to help identify needed resources and programs.
3. Implement and assess an on-line module for the newly diagnosed by May 1st;
4. As appropriate, share the program successes of other support groups with all leaders;
5. Explore the new technologies to make efficient and extend the reach of support resources; and
6. Ensure all electronic and written materials are medically accurate and presented in an appropriate manner/level for understanding.

S Objective 2: Ensure that those affected by dystonia have accurate information to make good treatment decisions and to know that they are not alone through availability of local resources such as support groups, regional contacts, physician referral and the DMRF Information &Referral line, etc.
Action Steps:
1. Work with existing support leaders and on-line moderators in their efforts to assist individuals/families in obtaining accurate dystonia information and coping/sharing opportunities;
2. Identify new support group leaders and provide the resources required for their success in becoming a local resource for those affected by dystonia and their families;
3. Review and revise job descriptions for area and regional contacts and confirm appointments to these positions by May 1, 2015;
4. Work with all network leaders to ensure they have what is needed to provide support and education to their respective communities;
5. Encourage leaders to have their local movement disorder neurologists join the DMRF physician referral list or if currently participating, to verify information and identify other movement disorder neurologists to join referral list;
6. Enlist leaders to bring DMRF materials to area physicians’ offices so patients have access to accurate, balanced educational materials;
7. Respond to inquiries/requests for information;
8. Support the work of regional and area contacts;
9. Promote new listings while confirming the contact information of existing listings on physician referral list.

**S Objective 3: Support educational and networking opportunities for affected persons/families.**

Action Steps:
1. Develop and implement a plan to develop support groups in key metropolitan areas;
2. In conjunction with our awareness & education efforts, host webinars – topics to be determined that will provide important information to identified audiences;
3. Maintain and monitor subject bulletin boards to ensure accurate information is being disseminated to ensure effectiveness of the resource;
4. Support and monitor social networking and encourage participation in these electronic networks.

**ORGANIZATIONAL CAPACITY**

The DMRF will work to ensure organizational integrity and efficiencies and organizational effectiveness.

**Org Objective 1: Ensure the Foundation’s operations are compliant with all applicable Federal, State and local laws and approved DMRF policies**

Action Steps:
1. Working with Audit Committee and outside financial consultant, ensure compliance with I.R.S. and Foundation fiscal and personnel policies and procedures;
2. Conduct 2014 audit and prepare for preliminary 2015 audit utilizing outside auditing services and conduct agreed upon procedures on Dystonia Coalition accounts;
3. Appoint a Tax Review Task Force to review 2014 taxes prior to filing;
4. Provide appropriate information to charitable rating organizations and monitor ratings;
5. Research, develop and implement a schedule for compliance with State and local charitable filing requirements;
6. Require completion of 2015 Board of Directors Code of Conduct Declaration Forms;
7. Conduct annual performance reviews on all DMRF staff;
8. Assess need for and then retain, as needed, insurance for DMRF sponsored events;
9. Utilizing a bidding process, work to ensure all expenses are contained.

**Org Objective 2: Strengthen and expand the Foundation’s Board of Directors**

Action Steps:
1. Working with the Nominating Committee identify individuals who will enhance the Foundation’s capacity;
2. Elect members of the Audit Committee at annual meeting of Board of Directors;
3. Provide an orientation to new Board Members;
4. Identify individuals for service on Foundation’s committees;
5. Ensure all Directors are apprised of Foundation activities, achievements and risks through regular communications from the Executive Director, and others as needed.

**Org Objective 3: Ensure efficient Foundation operations.**

Action Steps:
1. Develop and monitor operating budget to expenses monthly and issue monthly financial statements with a report on budget variances;
2. Develop and manage by individual staff working plans.
3. Manage the subtenant relationship, send renewal notice in January and promote availability of space if needed.