

CJD International Support Alliance Business Plan

Executive Summary

The CJD International Support Alliance (CJDISA) was formed by a group of grassroots nonprofit organizations that share one vital factor: a commitment to prion disease victims, their families, and those at risk for prion disease. CJDISA was founded to fill the gap that exists on an international level and to assure excellence in the service to individuals affected/at risk of prion disease, their families, and caregivers. The participating organizations are dedicated to work together in meeting the educational, social, emotional, spiritual and practical needs of those they represent. Under the CJDISA umbrella, these organizations collaborate on educational initiatives, information dissemination, resource allocation, program design and implementation, and advocacy.

The CJDISA was founded on the belief that by raising awareness of prion disease and educating healthcare professionals and the public at large, they could:

- Help remove the stigma surrounding CJD and other prion diseases.
- Promote research activities around early detection, prevention, treatment opportunities, improved quality of life and ultimately a cure.
- Increase proper utilization of resources.
- Promote continued access to care for those in active disease or those at risk for prion disease.
- Assist in ensuring safe blood and food supply

Membership

CJDISA membership currently includes the following organizations from around the world:

- CJD Support Group Network – Australia
- Associazione Italiana Encefalopatie da Prioni (A.I.En.P) - Italy
- CJD Support Network – Japan
- CJD Alliance – UK
- CJD Support Network – UK
- CJD Foundation – USA
- CJD Insight – USA
- CJD Foundation – Israel
- MCJ-HCC - France

As a CJDISA member, each organization continues to operate independently while benefiting from belonging to an international framework. The diversity of this group of organizations in experience and culture enriches the CJDISA with the knowledge, perspective, energy, passion, and creativity needed to achieve our goals and objectives. Many of the organizations have leadership and members that have been affected in some way by the loss of a loved one to prion disease and/or are themselves at risk for prion disease which provides intensity and commitment that is unparalleled.

CJDISA membership is open to any registered, legal, non-profit organization/entity in their individual country and who are dedicated to support the needs of those in active disease, those at risk of prion disease, their families and caregivers. CJDISA membership excludes medical professionals including physicians and/or researchers belonging to a member organization unless they have a personal experience/interest.

Members are free to withdraw or request a temporary leave of absence from the CJD International Support Alliance at any time, for any reason and without consequence or ill feelings. Conversely, the CJD International Support Alliance reserves the right to withdraw membership from an individual or organization at any time for failure to comply with the Alliance's goals, objectives, operating agreements or fundamental principles (refer to CJDISA Membership Agreement document).

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Operating Agreements:

The CJDISA will operate by consensus of all member organizations present; meaning each member organization can live with a decision being made and actively support the decision within the CJDISA and within their own organization. Consensus will be measured by open voting.

The following are operating agreements necessary for the team to be successful:

1. We participate fully and openly, while honoring the privacy of discussions.
2. We give feedback directly and openly in a timely fashion and we provide information that is specific and focuses on the task /issue as opposed to personalities or hidden agendas.
3. We focus on what the team will gain and the strengths we have rather than what individuals/organizations fear they will lose.
4. We respect that everyone brings something of value, talent, skill, resources, and understanding for a more effective, efficient organization.
5. We communicate effectively. One person talks at a time and all others listen with the commitment to understand the speaker's message.
6. We support and encourage all members to participate and share their experience, knowledge and ideas.
7. We are open to new ideas, change and the unknown.

Operating agreements will be reviewed periodically to make sure they still represent the commitment of the organization. When you notice participants actively upholding agreements, recognize them and express your appreciation. When someone fails to keep an agreement let the member know you expect him or her to behave as agreed. Close tolerance is required on those agreements in order to maintain an effective organization. At the same time, we must support diversity for it is one of the most valuable benefits of an effective organization.

Mission:

To work together as an international coalition on behalf of patients and families affected by prion disease the world over.

Vision:

Work together in meeting the educational, social, emotional, spiritual and practical needs of those we represent. Those we represent will be empowered by current, relevant information and support designed to meet their needs. By providing an interactive forum linking various prion disease support organizations, we promote the development of a highly improved care delivery system for those affected by prion disease through medical education, advocacy work, and the development of regulations that bring about positive change.

Goal(s):

Assure excellence in the service to individuals affected/at risk of prion disease, their families, and caregivers.

Objective(s):

- To always keep those we represent clearly in focus and to act only on those issues that benefit them.
- To remain impartial and free from political pressures and personal bias again, always keeping in mind those we represent.
- To share resources and information regarding prion disease research and, when appropriate, act together to report and publicize progress and hope from this research.
- To carry out activities on behalf of the Alliance only with mutual consent and with a unified global voice.

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- When we become concerned about an issue or issues we work together to make a united statement in an effort to bring about positive change.
- Maintain confidentiality

Strategy(ies):

The following are strategies which the CJDISA may engage in and reflect the immediate areas of concern for the countries currently represented. This list is not inclusive and will fluctuate depending on the advances made surrounding prion disease and the efforts of all involved organizations.

- Participate in activities, causes, and information gathering/dissemination activities that will support the needs of those we represent.
- Create a strong CJD/prion disease family network allowing for emotional, spiritual, financial, and information support to those we represent.
- Assist in creating a uniform system for 100% reporting of prion disease cases
- Actively engage in medical education (primary care physicians, ophthalmologists, neurologists etc.) and other care provider education (Home Care; Hospice; Genetic Counselors, Funeral Home Directors and those performing autopsies).
- Ensure access to medical and dental care through education and/or regulations.
- Collaborate with appropriate organizations to establish/revamp guidelines surrounding organ/blood donation especially for those who have little or no CJD risk.
- Develop a more empathetic and compassionate "care" model including education and guidelines surrounding autopsies, embalming techniques, and tissue donations for research purposes.
- Work with organizations to improve turn around time of autopsy results and genetic mutation results
- Collaborate with appropriate organizations to develop methods to properly inform and support people who are considered to be 'at risk of CJD'. This includes those who have a genetic predisposition to CJD, those who have received human pituitary hormones, a dura mater transplant or from a secondary transmission due to a blood transfusion and surgical instruments.
- Actively participate in advocacy work
- Promote research activities that focus on the etiology of prion disease, early detection techniques, treatments, and a cure.
- Encourage use and regulations that allow utilization of emerging therapies in a clinically controlled and monitored setting.
- Participate in the creation of adequate infection control guidelines related to prion disease.
- Promote activities and regulations that will ensure safe blood and food supply.

Client(s):

CJDISA clients include, first and foremost, prion disease victims, their families, and all those at risk of prion disease. In addition, our clients include CJD Support Agencies and researchers from across the world.

Client Benefits:

The CJDISA was founded on the belief that by raising awareness of prion disease and educating healthcare professionals and the public at large, they could:

- Help remove the stigma surrounding CJD and other prion diseases.
- Address the educational, social, emotional, spiritual and practical needs of those affected by prion disease.
- Promote research activities around early detection, prevention, treatment opportunities, improved quality of life and ultimately a cure.
- Increase proper utilization of resources.

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- Promote continued access to care for those in active disease or those at risk for prion disease.
- Assist in ensuring safe blood and food supply

Marketing/Communication Plan:

The marketing/communication plan focuses upon actions, which will create trust amongst our colleagues, and prion disease patients/families and generate excitement for the possibilities that the CJD International Support Alliance can bring to those we represent around the world. The marketing/communication approach will demonstrate the benefits of an international support alliance. This strategy will ensure a presence in all countries, communities and marketing spaces that increases awareness and builds demand for action.

Marketing vehicles include:

- Publications: Medical Journals, Healthcare Journals; and Government Journals.
- News Media.
- Each organizations websites.
- National and International Meetings.
- Brochures.
- Educational programs (Hospital Grand Rounds; educational workshops; presentations etc.).
- Educational DVD's.
- Fund Raising Activities.
- Sharing of information amongst all Prion Disease Support organizations.