



## Re: The Israeli Familial Dysautonomia Organization

### Project 365

#### About us

The Israeli Familial Dysautonomia Organization was founded in 1983 by parents of young people diagnosed with Familial Dysautonomia (FD). The organization's activities include promoting research, supporting medical centers and developing welfare and educational solutions. Additionally, the organization advocates for patients' rights to make decisions and contribute to relevant government policy. The organization is committed to raising awareness about FD, as well as its prevention, through advocating for genetic testing.

#### Our goals

- To support FD patients and their families in the areas of health, welfare and education
- To produce and disseminate information about the disease and its prevention amongst the general population
- To develop and finance research to develop new effective therapies for the disease
- To support medical centers which treat FD patients
- To ensure that every patient with FD, and their family, receive proper care and support.

#### About the disease

Familial dysautonomia is a Jewish Ashkenazi genetic disorder that afflicts that affects the development and survival of nerve cells in the autonomic nervous system. These nerves control involuntary actions such as digestion, breathing, production of tears, and the regulation of blood pressure and body temperature. It also affects the sensory nervous system, which controls activities related to the senses, such as taste and the perception of pain, heat and cold. Familial Dysautonomia is also called Riley-Day syndrome or hereditary sensory and autonomic neuropathy, type III.

#### Project 365

Project 365 was designed to answer the needs and challenges of the FD community, 365 days a year. Coping with the disease is challenging and highly dynamic. The sudden onset of seizures can lead to long-term hospital stays. FD can also lead to blindness, lack of balance, pneumonia, a dysfunctional digestive system, a feeding tube directly into the stomach, emotional challenges and more. In addition, people with FD and their families may suffer from loneliness and other emotional issues that require ongoing support.

Due to the very small number patients worldwide (less than 500), FD is considered an ultra orphan disease, which has too small a population to be commercially attractive for pharmaceutical companies to invest the huge resources required to discover and develop effective new treatments, or even a cure.

Project 365 was created to provide focused and comprehensive solutions to these ongoing challenges. This life-saving project has been designed to meet the specific needs of the FD community. Many factors are considered when designing support services. These include patients' area of residence, age, gender and communal affiliation.

**Project 365 provides:**

Ongoing support and support groups that:-

- Are run by professionally trained support teams
- Help to foster the development of individual skills and abilities
- Are tailored to meet the specific needs of people in different age groups
- Assist families in organizing and keeping track of their medical records, treatments and testing. This in turn helps medical facilities to conduct research and improve services for the FD community.

In addition, the FD community benefits from periodic educational workshops and leisure activities. These include:-

- Vacations (for families and for individual patients accompanied by support staff, as necessary)
- Trips
- Events on holidays
- Social activities

**Medical Equipment**

Project 365 also assists families by purchasing and maintaining medical equipment for them. This includes:-

- watches that measure essential body metrics
- portable oxygen generators
- additional respiratory equipment that is necessary for physiotherapy and more.

The total annual cost of Project 365 is \$150,000. Resources are allocated in accordance with the priorities of the organisation, and are divided between:-

- Rent (including payment for spaces where activities are held)
- Project management
- Salaries for six professionals who regularly meet with the groups and accompany patients and their families
- Payments for one-time projects.

All of our funding comes from donations, except a minor symbolic contribution that we charge the families for participating in the programme.

Please be so kind as to help to support our life-saving project that will help us to continue our activities - [Click here for the support page](#)

I appreciate your consideration, and am available to answer any questions you may have.

Sincerely,

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