



## Re: The Israeli Association for Family Dysautonomia, 365 program

### About us

The Israeli Association for Family Dysautonomia was founded in 1983 by parents of youth diagnosed with Familial Dysautonomia (FD). The association's activities promote research, support medical centers, develop appropriate welfare and educational solutions, and advocate patient's rights to decision and policymakers. The association is committed to raising awareness about FD, as well as prevention, through advocating for genetic testing.

### Our Goals

- Support FD patients and their families in the areas of health, welfare, and education.
- Producing and disseminating information about the disease and its prevention among the general population.
- Developing and financing research to treat the disease.
- Supporting medical centers which treat FD patients.
- Ensuring that every patient with FD and their family receives proper care and support.

### About the disease

Familial dysautonomia is a genetic disorder 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 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, a lack of balance, pneumonia, a dysfunctional digestive system, a feeding tube directly to 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.

FD is often called an "orphan" disease because, due to its rarity, the medical and pharma industries do not channel resources or investments into finding a cure.

Project 365 was developed 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. Some of these are their area of residence, age, gender (if they prefer), and type of community affiliation.

Project 365 provides:

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

In addition, the FD community benefits from periodic educational workshops and leisure activities, including:

- Vacations (both 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 the families. Some of this equipment includes:

- Watches that measure essential body metrics
- Oxygen generators
- Additional respiratory equipment that is necessary for physiotherapy, and more.

The total annual cost of Project 365 is \$ 200,000. Resources are allocated modularly, and in accordance with the priorities of the organization and are divided between:

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

All of our funding comes from donations, except a minor, symbolic fee we charge the parents for participating in the program.

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

Sincerely,

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