



Jeffrey Modell
Foundation

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Curing PI.
Worldwide.

Jeffrey Modell Foundation

Code of Ethics

I. Mission

Vicki and Fred Modell created the Jeffrey Modell Foundation, a 501(c)3 nonprofit organization, in memory of their son Jeffrey, who died in 1986 at the age of fifteen from complications of Primary Immunodeficiency – a genetic condition that is chronic, serious, and often fatal. JMF is a global patient organization devoted to early and precise diagnosis, meaningful treatments, and ultimately, cures - through clinical and basic research, physician education, patient support, advocacy, public awareness and newborn screening.

II. Personal and Professional Integrity

All staff, Board Members, and volunteers of the Jeffrey Modell Foundation, should act with honesty, integrity and openness in their dealings as representatives of the Foundation. The Foundation promotes a working environment that values respect, fairness, and integrity.

III. Governance

- Directors must have the requisite skills and experience to carry out their duties and that members understand and fulfill their governance duties acting for the benefit of the Foundation and its public purpose.
- The Foundation's management promotes working relationships with Board Members, staff and program beneficiaries that are based on mutual respect, fairness, and openness.
- The Foundation's management and Board of Directors are responsible for oversight, including the capacity to carry out the Foundation's programs effectively.

IV. Fundraising

The Foundation is truthful in its solicitation materials, respects the privacy concerns of individual donors, and expends funds consistently with the donor's intent. The Foundation discloses important and relevant information to potential donors.

In raising funds from the public, the Foundation will respect the rights of donors, as follows:

- The Foundation informs donors of its mission, the way in which resources will be used and its capacity to use donations effectively for the intended purposes;
- The Foundation assures donors that their gifts will be used for the purpose in which they were intended;
- The Foundation provides appropriate acknowledgement and recognition;

- The Foundation assures donors that information about their donations is handled with respect and with confidentiality (to the extent provided by the law);
The Foundation will provide prompt, truthful, and forthright answers to the best of its ability in responding to donors' questions regarding donations.

V. Accountability and Transparency Policies

1. **Conflict of Interest Policy** - The Members of the Board of Directors hold a legal and fiduciary responsibility for the operations of the Foundation. The Board is a diverse group of independent members plus the Officers, who bring a variety of expertise to the governance of the Foundation.

Members of the Board and Officers of the Foundation are selected solely on the basis of an unquestioned desire to promote the best interests of the Foundation and the public good without the taint of actual or potential conflicts of interest.

The Foundation's integrity must be protected and advanced at all times. The Foundation recognizes that Members of the Board and Officers of the Foundation could have potential conflicts of interest and any potential conflicts are monitored and reviewed by the Foundation's Officers and independent advisors.

2. **Whistleblower Policy** - The Jeffrey Modell Foundation encourages all employees to report financial management issues or complaints to the Executive Director and Officers of the Foundation. Employees that wish to report a specific financial issue are required to report those issues, in confidence, in the following order:

1. Executive Director
2. Officers of the Foundation
3. The Independent Certified Public Accountants

3. **Records Retention Policy** - The Jeffrey Modell Foundation retains all records including financial, contracts, and program agreements for a minimum of seven years. Certain records such as Board meeting minutes, tax returns, and other critical material matters are continually retained. These records are secured at the offices of the Jeffrey Modell Foundation and at a records warehouse that has provided sound service to the Jeffrey Modell Foundation for more than 15 years.

4. **Process for Determining CEO Compensation** - The process utilizes the following protocol:

1. Comparability studies serve as a guideline. These are readily available on numerous public Websites, based on services performed.
2. Recommendations from the Foundation's independent public auditors and other outside advisory firms.
3. Review of financial matters by the Jeffrey Modell Foundation Board of Directors at its Annual Meeting.

5. **Donor Privacy Policy** - The Jeffrey Modell Foundation (JMF) clearly states that it will not trade, share, or sell a donor's personal information with anyone, nor send mailings to donors on behalf of any other organization. There are no exceptions!

6. List of Board Members

Jeffrey Modell Foundation Board of Directors

Vicki and Fred Modell Co-Founders

Marillyn Abrams	Lisa & Steve Lawrence
Hassan Ahmed	Debbi & Max Lebersfeld
Felice Axelrod	Debbe Longo Strout
Madaleine Berley & Arnold Penner	Wendy & Jonathan Mechanic, Esq.
Helen Chaitman, Esq.	Shelby Modell
Jennifer Chaitman, DVM	Jodi Pulice & Greg Smith
Bettina Emden	Carol & James Randel
Frann & Eric Francis	Aby Rosen
Robbie & Alan Franklin, Esq.	Jason Shuman
Allyson & Alan Galishoff	Lisa & Stephen Shuman
Laureine & David Greenbaum	Wendy & Stephen Siegel
Patricia & Edward Gutman	Luciana & Michael Solomon
Donna Harvey	Susan & Barry Stein, MD
Kurt Hirschhorn, MD	Allyson & Philip M. Waterman III
Rochelle Hirschhorn, MD	Lisa & William Wexler
Mitchell Konsker	Steven Witkoff
Brenda & Gary LaVigna	

7. **Compensation of Board Members** – No Directors are compensated with the exception of the Co-Founders as stated on the Form 990 tax return.

8. **Form 990** – [The Jeffrey Modell Foundation provides continuing access to Form 990, which is linked to Charity Navigator.](#) If you have any difficulty accessing these documents, please contact the Jeffrey Modell Foundation.

9. Key Staff

Fred Modell	Co-Founder
Vicki Modell	Co-Founder
Vanessa Tenenbaum	Executive Director
Jo Ann Fortunato	Chief Financial Officer
Jessica Quinn, MPH	Scientific Director