



## Board Member

# JOB DESCRIPTION

### EXPECTATIONS OF THE BOARD AS A WHOLE

The mission of The DESSH Foundation is to raise awareness of DeSanto-Shinawi Syndrome (DESSH) among the medical profession and the general public, to advance research and education related to DESSH, and to provide a support-community for patients and families challenged by DESSH.

As the highest leadership body of the organization and to satisfy its fiduciary duties, the board is responsible for

- determining the mission and purposes of the organization, and adhering to them
- strategic and organizational planning
- ensuring strong fiduciary oversight and financial management
- fundraising and resource development
- approving and monitoring The DESSH Foundation's programs and services
- enhancing The DESSH Foundation's public image
- assessing its own performance as the governing body of The DESSH Foundation
- selecting and evaluating the performance of the CEO/executive director, if applicable

### EXPECTATIONS OF INDIVIDUAL BOARD MEMBERS

Each individual board member is expected to

- know the organization's mission, policies, programs, and needs
- faithfully read and understand the organization's financial statements
- prepare for, attend, and conscientiously participate in board meetings
- serve as active advocates and ambassadors for The DESSH Foundation
- leverage personal connections, networks, and resources that can benefit the organization's fundraising, and/or support its patient population, and/or raise awareness through media attention
- fully engage in identifying and securing the financial resources and partnerships necessary to advance the organization's mission
- give a meaningful personal financial donation or prompt a personal fundraising campaign
- Pursue education related to rare disease stakeholders and its research infrastructure
- actively engage with the organization's patient community

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### BOARD MEMBERS ARE ALSO EXPECTED TO

- follow the organization's bylaws, policies, and board resolutions
- sign a conflict-of-interest disclosure and update it if necessary, as well as disclose potential conflicts before meetings and actual conflicts during meetings
- maintain confidentiality about all internal matters of The DESSH Foundation