

# Liv4TheCure

## Board Member Responsibilities



The Liv4TheCure Board of Directors holds governance responsibility for the organization. In this role, Board members act as stewards of the mission and work to assure the activities of the organization serve the mission.

This is accomplished through:

- Establishing and monitoring the organization's strategic direction
- Monitoring of program effectiveness and scope
- Establishing and funding adequate operating budgets
- Advocating for the organization in the community and in the member's business and social circles
- Maintaining the capacity of the Board to accomplish its goals

Each member is expected to:

- Maintain regular attendance at Board meetings and committee meetings
  - Bylaws required that members miss no more than two meetings annually without excuse and prior notification
- Serve on one of the following committees
  - Finance
  - Fundraising & Special Events
  - Marketing
  - Recruitment
  - Research & Science
- Be actively engaged in Board and committee discussions and decisions
- Participate in all fundraising events (unless excused with prior notification)
- Actively participate in the donor cultivation programs of the Board
- Provide monetary support to the organization
- Assist with the solicitation of fundraising support to reach a total annual give/get of
- Support the recruitment of new Board members

In addition to the Board and member roles listed above, it is expected that the talent and community commitment brought by each member will be available to the Board and organization in terms of input and creativity leading to advancement of the mission and improved community impact.

## What does board membership entail?

### Responsibilities

The primary responsibilities of the board are governance, strategic planning and fund development. Board members continuously monitor progress of budget and program goals.

### Time Commitment

Attendance at board, committee meetings and other organizational events is key to the success of Board member and the realization of Liv4TheCure's mission and goals. Although many worry of the time constraint, on average, our board members spend one hour a month working with Liv4TheCure. There are 6 board meetings a year and most committees meet monthly. There are other events that board members participate in such as fundraisers and community volunteer opportunities.

### Advocacy

Board members are the leading force behind spreading awareness of Liv4TheCure's mission and purpose. Members are expected to champion the Liv4TheCure mission in the community on a regular basis.

### Qualifications

Individuals with a strong desire to support and further research into Wolf Hirschhorn Syndrome and chromosomal deletion syndromes, as well as gene therapy and replacement are the ideal candidates for board membership. Additionally, people with a wide-reaching network are highly desirable candidates.

## About Liv4TheCure

Liv4TheCure's mission is to advance science and technology for rare chromosomal deletion syndromes, with a special focus on Wolf Hirschhorn Syndrome.

Our goal is to bring awareness to rare diseases, specifically Wolf Hirschhorn Syndrome which is a genetic deletion on the 4th chromosome that affects children in highly varied ways. All funds will go to research, specifically gene therapy and replacement for the missing areas of the 4th chromosome that have been deleted.

Liv4TheCure wants to fund the creation of a new platform technology such as CRISPR that will not only help children with WHS but any child with a genetic deletion.