

Strategic Plan

Huntington's Disease Tasmania Inc

2020 – 2022

September 2020



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Background

1. Huntington's Disease Tasmania is an Incorporated Association, established in 1978 and incorporated in 1983 to develop educational programs and provide support for Tasmanians affected by Huntington's Disease.
2. Huntington's Disease Tasmania is governed by a volunteer Board. The Board has no employed staff relying on Board members to provide work at both strategic and operational aspects of the Association's work.
3. Broadly, Huntington's is a degenerative neurological disease of the brain caused by a defective gene that is passed from parent to child. The gene interferes with the manufacture of a particular protein called Huntington which appears to be crucial for proper brain development. The classic signs of Huntington's Disease include emotional, cognitive and motor disturbances. There is currently no cure for Huntington's Disease. Whilst there are a number of medications to help control emotional and movement problems, there is no treatment to stop or reverse the course of the disease.
4. Every child of a gene positive parent has a 50% chance of inheriting the disease.
5. According to Tasmanian statistics Huntington's disease affects 1 in 5,000 individuals, this does not include those that are considered at risk or pre-symptomatic. For every gene positive person it is estimated that there are 5 people at risk of inheriting the disease.
6. Per capita, Tasmania has the second highest prevalence of Huntington's disease in the world.
7. This may be due to an individual with Huntington's Disease settling in Tasmania many years ago and passing on the expanded HTT gene; this is known as the founder effect.

The Plan

1. This Strategic Plan refers to the period 2020 to 2022 and sets out the issues, objectives, strategies, performance measures and standards to be achieved by Huntington's Disease Tasmania (HDT).
2. The plan is deliberately focused at the strategic and policy levels. Within Huntington's Disease Tasmania other plans address issues and objectives at the operational levels.
3. The implementation of the strategic plan is the responsibility of Huntington's Disease Tasmania board of directors. Currently HDT has no employed staff relying on Board members to provide work at both strategic and operational aspects of the Association's work

4. The plan is designed to be implemented involving actions to be achieved on a month by month basis for the first year (2020 – 2021) with actions for years 2 and 3, documented on an annual basis.
5. The plan will be reviewed annually and involve examining performance with regard to current issues, objectives and strategies prior to establishing the next 12 month strategic action plan based on the current strategic plan.

Huntington's Disease Tasmania Vision, Mission and Values

Vision

The Huntington's Disease community in Tasmania has the information, support, resources and recognition required to effectively manage the disease in Tasmania.

Mission

Committed to the provision of education, information, advocacy and support to people with Huntington's Disease, their carers, families and the wider community.

Values: For all who are part of Huntington's Disease Tasmania

1. Establishment and maintenance of relationships with our stakeholders and community which are based upon openness, trust, fairness, honesty, integrity, caring and confidence.
2. Respect for individuals and appreciation for the contributions that each can make.
3. Encouraging member pride, enthusiasm, compassion and inclusion.
4. The recognition of the value of tenacity, perseverance, experience

Guiding Principles

1. Person Centred
2. Family Focus
3. Consideration of health, social and psychological impacts of HD
4. Customised provision of assistance
5. Maximising the quality of life for clients and their families

Strategic Plan for Huntington's Disease Tasmania Inc

The Structure of the Plan

1. This Strategic Plan has been prepared by the Board of Huntington's disease Tasmania Inc (HDT Inc) and has the following structure. The core information is represented as two

tables, a Strategic Directions Plan (what areas we have to work on) and a Strategic Action Plan (what work has to be done in each area).

2. The reason for the tabular format is that it is clearer to see the plan as a whole and, it is easy to see which objectives, strategies, measures and targets refer to which critical areas HDT is focusing on and, which issues/opportunities they relate to.
3. The Plan is deliberately strategic and focusses on the bigger picture and longer term relating to HDT Inc. It does not attempt to provide all the answers but indicates the prioritised areas HDT Inc should work on including the work that needs to be done to determine the where the company should best place its efforts.
4. The plans are structured as follows:

a. **Strategic Directions Plan (Table One)**

- I. **Areas of Critical Focus** – the main areas in which HDT Inc focusses its activities.
- II. **Strategic Issues** - 6 – 8 key issues and opportunities HDT Inc needs to address over the next 3 years.
- III. **Strategic Objectives** – What the Board wishes to achieve in relation to each strategic issue or opportunity.
- IV. **Strategies** – What is the broad approach the Board wishes to take in order to achieve each strategic objective.
- V. **Performance Measures** – What things will the Board need to measure to help it determine whether strategic objectives have been reached.
- VI. **Targets** – How well does the Board wish the organisation to perform against each measure.

- b. **Strategic Implementation Plan (Table Two)** – This table sets out what tasks need to be done, when the tasks need to be done by, who is going to do them and how much each task will cost. The implementation plan will be set out on a month by month basis for the first 12 months and then, on a year by year basis after that.

Areas of Critical Focus

1. From the outside looking in, HDT Inc has identified three areas that it focusses on:
 - a. The lack of a professionally operated organisation that is sustainable over the medium to long term;
 - b. The Huntington's Disease community does not receive the resources and support it needs due to low level professional and community awareness of the disease; and,
 - c. The Huntington's Disease community does not have the knowledge, information and tools required to best manage the disease within their families.
2. The strategic plan then identifies the issues that HDT Inc will address that will enable the organisation to continue the provision of education, information, advocacy and support to people with Huntington's Disease, their carers, families and the wider community and, to ensure that HDT Inc has the capacity and capability to maintain a sustainable organisation.
3. The issues identified should not be seen as criticisms of HDT Inc's current activities but should be seen as areas that HDT Inc need to continue to work on if it is to achieve its organisational vision.

Strategic Objectives

When the HDT Inch as addressed these issues, it will have achieved the following strategic objectives:

1. Huntington's Disease Inc (HDI) has access to the resources required to ensure it can provide the necessary support to the Huntington's Disease community within Tasmania;
2. HDI has the resources required to govern and manage the organisation in a professional manner;
3. Relevant health professionals is aware of the issues, information and resources required to assist the Tasmanian Huntington's Disease community to effectively manage the disease;
4. The mainstream community is aware of the nature, issues and circumstances associated with the prevalence and management of the disease in Tasmania to the extent that it is supportive of the activities of HDI in Tasmania; and,
5. The Huntington's Disease community has the knowledge, information, tools and support it requires to best manage the disease within Tasmania and each family.

Strategies to Achieve Objectives

In relation to the first critical area of focus relating to developing a professionally operated and sustainable organisation, the Board has identified the following strategies:

1. Preparation and completion of annual activity plans that sets out the tasks required to provide the necessary support to the Huntington's Disease community within Tasmania.
2. Preparation and completion of the nature and extent of physical, human, intellectual and financial resources at both governance and operational levels required to achieve HDT's strategic direction and implement annual activity plans over the medium to long term (3 – 10 years).
3. Preparation and completion of a plan to procure resources identified.

Performance Measures and Targets

1. The Board of HDT Inch as identified a range of performance measures and targets that relate to each strategy (see Strategic Directions, Table One, table below).
2. The same structure and process applies to the second critical area of focus, "The Huntington's Disease community does not receive the resources and support due to low level professional and community awareness of the disease."

Table One Huntington’s Disease Strategic Directions Plan

Issue/Opportunity	Objective	Strategy	Performance Measure	Target
Lack of a professionally operated organisation that is sustainable over the medium to long term.	1. Huntington’s Disease Inc (HDI) has access to the resources required to ensure it can provide the necessary support to the Huntington’s Disease community within Tasmania.	1. Preparation and completion of annual activity plans that sets out the tasks required to provide the necessary support to the Huntington’s Disease community within Tasmania.	1. Completion of annual activity plans.	1. October 2020
	2. HDI has the resources required to govern and manage the organisation in a professional manner.	2. Preparation and completion of the nature and extent of physical, human, intellectual and financial resources at both governance and operational levels required to achieve HDT’s strategic direction and implement annual activity plans over the medium to long term (3 – 10 years).	2. Completion of resource requirements plan.	2. November 2020
		3. Preparation and completion of a plan to procure resources identified.	3. Commencement of resource procurement plan starting with funding Business Case submitted	3. February 2021 4. March 2021

Issue/Opportunity	Objective	Strategy	Performance Measure	Target
			to Tasmanian Health Service. 4. Recruitment of Executive Officer	April 2021
The Huntington's Disease community does not receive the resources and support due to low level professional and community awareness of the disease.	1. Relevant health professionals is aware of the issues, information and resources required to assist the Tasmanian Huntington's Disease community to effectively manage the disease.	1. HDI to identify the nature and content of the issues, information and resources required for health professionals within Tasmania regarding Huntington's Disease within the State.	1. Content of the issues, information and resources documents completed.	1. July 2021
	2. The mainstream community is aware of the nature, issues and circumstances associated with the prevalence and management of the disease in Tasmania to the extent that it is supportive of the activities of HDI in Tasmania.	2. HDI to prepare a marketing plan to promote the issues, information and resources required for health professionals within Tasmania regarding Huntington's Disease.	2. Marketing plan completed. 3. Implementation of marketing plan commenced.	2. August 2021 3. October 2021
Huntington's Disease community does not have the knowledge, information and tools required to best manage the disease within their families.	The Huntington's Disease community has the knowledge, information, tools and support it requires to best manage the disease within Tasmania and each family.	1. HDI to identify the nature and content of the knowledge, information and tools required for the Huntington's Disease community within Tasmania to best	1. Content of the knowledge, information and tools documents completed.	1. February 2022

Issue/Opportunity	Objective	Strategy	Performance Measure	Target
		manage the disease within Tasmania and each family.		
		2. HDI to prepare a marketing plan to promote the knowledge, information and tools required for families managing Huntington's Disease.	2. Marketing plan completed.	2. May 2022
			3. Implementation of marketing plan commenced	3. July 2022

Table Two Huntington’s Disease Strategic Implementation Plan

Issue/Opportunity	Task	By When	By Who
Lack of a professional operated organisation that is sustainable over the medium to long term.	1. Completion of annual activity plans.	October 2020	HDT Board
	2. Completion of resource requirements plan.	November 2020	HDT Board Moore Consulting
	3. Commencement of resource procurement plan starting with funding Business Case submitted to Tasmanian Health Service.	February 2021	HDT Board Moore Consulting
	4. Complete review of HDT Board of directors.	November 2020	HDT Board Moore Consulting
	5. Prepare plan to address any gaps identified	November 2020	HDT Board Moore Consulting
	6. Recruitment and procurement of HDT Executive Officer	April 2021	HDT Board Key Stakeholders
The Huntington’s Disease community does not receive the resources and support due to low level professional and community awareness of the disease.	Content of the issues, information and resources documents completed.	July 2021	HDT EO HDT Board
	3. Marketing plan for industry professionals	August 2021	HDT EO HDT Board

Issue/Opportunity	Task	By When	By Who
	completed. 4. Implementation of marketing plan commenced	October 2021	
Huntington’s Disease community does not have the knowledge, information and tools required to best manage the disease within their families.	1. Content of the knowledge, information and tools documents completed. 2. Marketing plan completed. 3. Implementation of marketing plan commenced	February 2022 May 2022 July 2022	HDT EO HDT Board HDT EO HDT Board HDT EO HDT Board