

# FACS New Zealand Strategic Priorities and Goals 2021 - 2025



## **Priority 1: Awareness Raising**

Goal 1: The syndromes/spectrum disorder is known and recognised by medical professionals.

Goal 2: Parents and families have access to a range of sources of information to enable them to make informed consent and choice.

## **Priority 2: Research**

Goal 1: The full extent of the problem is known and we have solid data to share.

## **Priority 3: Support for individuals and families who have been exposed**

Goal 1: All individuals and families are empowered to help themselves and each other.

## **Priority 4: Restorative practice**

Goal 1: Families have the opportunity to heal and prevention strategies are in place for others.

## **Priority 5: Organisation development**

Goal 1: FACS NZ is a stable organisation.



Last updated: 13<sup>th</sup> September 2021



# FACS New Zealand Strategic Priorities

2021 – 2025

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## Our Vision

Every person of childbearing potential who is on seizure controlling medicine(s) has the necessary information to give informed consent and informed choice.

People who have been exposed to anti-seizure medicine(s) during pregnancy lead a life where they can reach their own potential.

# Our mission

- Advocate and problem solve with those individuals and groups affected.
- Educate interested parties.
- Support health professionals and families (listening, advice).
- Collaborate on designing pathways for diagnosis.
- Support research into the effects of anti-seizure medicines.
- Awareness raising.
- Collaborate with other organisations.
- Provide foundations for a community.

*We do not provide medical or health care advice.*



# Priority 1 – Awareness Raising

Goal: The syndromes/spectrum disorder is known and recognised by medical professionals.

## Indicators of success:

1. Policy frameworks are changed to prioritise people's safety.
2. Mandatory guidelines are in place for prescribing anti-seizure medicine(s).
3. Presentation of medicine(s) contains accurate information for users including visually.
4. Grand rounds are facilitated.
5. ACC prevention work is carried out.

Goal: Parents and families have access to a range of sources of information to enable them to make informed consent and choice.

## Indicators of success:

1. Information is disseminated.
2. Targeted social media is active on the issue.
3. GPs are supplied with brochures.
4. A credible information website is maintained.
5. Media exposure is active.
6. School newsletters contain information.
7. Partners disseminate information through to families.





## Priority 2 – Research

Goal: The full extent of the problem is known and we have solid data to share.

### Indicators of success:

1. Current research and researchers are identified.
2. Existing data and research is collated.
3. Coding of data collection is in place.
4. A parent survey has been completed.
5. Collaboration is carried out with international researchers.



## Priority 3 – Support for individuals and families who have been exposed

Goal: All individuals and families are empowered to help themselves and each other.

### Indicators of success:

1. The foundations for a community are in place.
  - Facebook pages are maintained.
  - A mailing list is operated.
  - Conferences are co-ordinated.
  - Conversations and support are offered to reduce isolation.
2. Individuals and families have access to appropriate advocacy.
  - Formal support mechanisms are identified and shared.
  - Pathways are identified.
  - Referrals are provided to the right specialists.
3. Current evidence-based information is available
  - Booklets are produced for distribution.
  - Current information is curated and distributed.
4. Individuals and families get government support.



## Priority 4- Restorative Practice

Goal: Families have the opportunity to heal and prevention strategies are in place for others.

### Indicators of success:

1. Individuals and families are supported to collate and tell their story (how to tell their stories and receive professional support from telling their story).
2. Trustees and staff have knowledge on restorative practice.
3. Panels are situated across geographical locations and we inform the make-up of panels.



# Priority 5 – Organisation Development

Goal: FACS NZ is a stable organisation.

## Indicators of success:

1. We have staff on the ground:
  - Executive Officer stays in a high-level role.
  - A Support Worker for families is in place.
  - Administration support is in place.
2. A fundraising strategy is developed and initiated to ensure we have sufficient funding to pay staff and provide support.
3. A pro bono/volunteer fundraiser is secured.
4. Relevant policies and procedures are developed.
5. Community connections are built to support succession of the Board and sustainability of the organisation.
6. The Board has additional Trustees in place, including Pasifika and Māori.
7. Partners who are doing similar work are identified and engaged.

