HELLO
DEVELOPING A NATIONAL ASSOCIATION.

- The importance of setting clear Vision, Mission and Objective.
- The Importance of Strategic Roadmap.
- Action Plan.
- To mobilize, empower and build up a network.
The Importance of Clear Vision, Mission & Objective

Clear Vision and Mission will entice them to be a member.

2. Planning

Clear objective will lead to proper planning.

Planning should plan for a strategic roadmap to achieve the objective.

Recruitment

Patients, parents, caregivers and family members.
Vision
➢ To create a Support Group.
➢ To create network and awareness among public, patients and family.

Mission
➢ Access to subsidized Growth Hormone Treatment within 5 years.

Objective
➢ Towards improved PWS Person Outcome and to prepare for their Independent Living.

TeamWork
Is the keyword for success.

To achieve, we need a good engagement with all parties / stakeholders.
Impactful Awareness

2. Will leverage for supports

Objectives
Towards improved PWS Person Outcome and to prepare for their Independent Living.

80% INCREASE awareness

20% Leverage Network

Members Recruitment
To create High Impact
Data Collection
Our main priority.

3. DATA MANAGEMENT
Data management is the most important element in our planning processes.

Good data collection will lead to a better planning.
AGE GROUP

TOTAL = 125 Patients

Below 6 yrs Age Group

7 - 12 yrs Age Group (Primary)

13 - 17 yrs Age Group (Secondary)

17 and above Age Group

40

51

18

16
AGE GROUP INFOGRAPHIC
PERCENTAGE CHART

- **ABOVE 17 YEARS OLD**
  - 16 patients
  - Oldest 25 yrs old
- **BELLOW 6 YEARS OLD**
  - 51 patients
- **13 - 17 YEARS OLD**
  - 18 patients
- **7 - 12 YEARS OLD**
  - 40 patients
- **41%**
- **32%**
- **15%**
- **13%**
MALE VS FEMALE

CHART

57% MALE
Male – 71 patients

43% FEMALE
Female – 54 patients
The Importance of Strategic Roadmap
Professional Awareness and Support is vital for us,
➢ Ongoing Research, Education & Innovation.
➢ Multidisciplinary clinical & Caregiving Best Practise.
➢ Well Informed Families & Special Needs Educators.

Research University.
❑ To develop research based credentials.

Public and Private Hospital.
❑ Pioneering & Passionate Clinicians.

Allied Health Service Provider.
❑ To provide best practice Lifelong Intervention Program.

Child Development & Special Needs Educators.
❑ To develop their needs and prepare them for Independent Living.
Strategic Roadmap
Professional Awareness and Support

Public & Private Hospital
- To develop Passionate Multidiscipline Clinician.
  - 45%

Child Development / Special Need Education Provider
- To develop Independent Living Skills.
  - 35%

Research University
- To develop Research Based Credentials.
  - 25%

Allied Health Service Provider
- To develop Multidisciplinary Caregiving Best Practices.
  - 65%

* The percentage is just the analogy to show the importance of the subject.
Investment Infographic
Professional Awareness & Support

University

Public & Private Hospital

Allied Health Services

Child Dev. Special Needs Education

Research Program

Lifelong Intervention Program

Clinical Program

Special Need Education
The most important element

- PWS residence with rehab & certified Caregivers.
- Access to subsidized Treatment.

- Pharmaceutical Industry
- Corporate Social Responsibility Program.
- Government Policy
The Game Changer.

- The important group.

- Impacting equitable coverage.
- Raise awareness and enhance visibility of PWS in all sectors including health, social, work, education and research.

Pharmaceutical Industry
To advance and promote knowledge about medication and to ensure the availability and affordable of the drugs.

Government Policy
To promote and enhance services in the healthcare, education, training, employment, welfare and other support services for patients and families.

Corporate Social Responsibility Program
To relieve financial hardship of patients and families affected with PWS.
Improve Person with PWS

Government /Policy

Corporate CSR
Fund
To relieve financial hardship & create empathy.

Governance & Policy
Will enhance and improve the life of patients and families.

Pharmaceutical Industries
Clinical & Allied Health
Pharmaceutical, Clinical & Allied Health Service Provider
Important entities in preparing the person with PWS towards their independent living.
ACTION PWS PLAN
Governance & Policy Maker
- To enhance services in the healthcare, education, training, employment, welfare and other support services for patients and families.

Contract
- Passionate Clinicians, Allied Health Services Provider, Child Development Centers and Special Needs Educators plays important roles.

Research
- To advance and promote knowledge and education by engaging in, encouraging and supporting research in PWS

Planning
- ✓ Good planning with clear direction will create a good result.

Communication
- ✓ Engagement with all parties / stakeholders in the ecosystem with accurate information is vital.
- ✓ Awareness Program is on going process.

Analysis
- ✓ Good analysis will lead us to a better priorities.
To mobilize, empower NETWORK And build up
Mobilization & Empowerment

Governance & Policy
To support & enhance and to ensure the governance of all the policy.

Professional Awareness & Support
To support and enhance

Association
Mobilize all the resources

Research
To provide the credentials needs.
EMPOWERMENT

Communication
➢ Accurate information

Planning
➢ To mobilize and empower the right person

Analysis
➢ Priorities the needs.

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Build up a Network
To reach out all the stakeholders in the ecosystem.

To establish network of association with organizations, agencies and professionals involves in providing treatments, training and education to the patients and families.

Government & Ministry.
- Policy maker.

Professional Awareness & Support.
- Important network in the Lifelong Journey.

Funds
- Ensure a good work-life balance and protection from loss of income for family members who are caregivers.

Time & Technology.
- To reach out with effective time.

Government Policy
Professional Awareness & support
Success!
Big Deal FUND
Time Technology
Working with different stakeholders in the ecosystem.

Passionate & Advocacy

Good Mindset

- We need to start first.
- Unite & togetherness make us stronger and resilient.
- Be focus
We can save PWS community.

Network around the Globe.

**Better Understanding about PWS.**
Make the impactful & our presence felt!!

No One Left Behind
www.pwsamalaysia.org.my
Strive Together WE can do it !!!
THANK YOU
PWSA