# Building a strategic plan for 2025-27



An overview of what we're working towards over the next 3 years.



SCAN TO FOLLOW ALONG

Naevus Global Conference 22-23 April 2025 Prague, Czech Republic



Part 1:

Mission, Vision, Values

Part 2:

3-Year Strategic Objectives

Part 3:

Action Plan & Key Performance Indicators

Part 4:

Summary & Future Planning

## Steering Committee 2025



Benjamin Loeffler

Naevus Netzwerk, Germany



Inbal Travis Engler

Children of Light, Israel



Marjolein van Kessel

Nevus Netwerk Nederland



Sieglinde McKeown

Nevus Association South Africa



**Whitney Casal** 

Nevus Outreach, USA / Germany

#### LOOKING BACK

- 2024 Meeting
  - 15-16 June 2024
  - Paris, France
  - 20 CMN patient representatives from 12 countries
  - Missions, Vision, Values, Strategy
- Naevus Global Survey, conducted by Redmond Consulting March 2024
  - Identifying our current community
  - Ranking challenges associated with CMN
  - Gauging interest and direction of Naevus Global



NAEVUS GLOBAL 2024 MEETING MINUTES



NAEVUS GLOBAL
PRESENTATION + SURVEY
FINDINGS 2024









## Naevus Global is uniquely placed to do to address community needs:

- **Empower** CMN patient organisations across the world to be more effective in their activities.
- **Connect** the global CMN patient community by providing a platform for knowledge exchange, addressing common problems, sharing resources, and codeveloping common resources.
- **Coordinate** joint action to address common problems (e.g. raise awareness about the burdens of CMN and the need for greater policy prioritisation, promote research on CMN/NCM, address access problems, etc.)
- Provide a united and representative patient voice in global decisions that impact on people with CMN

## Part 1

Mission, Vision, Values

#### UPDATED MISSION

Naevus Global is an international network of patient representatives, committed to enhancing the lives of those affected by CMN.

We connect and empower the patient community, channel our collective expertise, and amplify our unified voice to influence global decisions that impact our community.



#### UPDATED VISION

A strong and impactful network of patient representatives working together to ensure people affected by CMN enjoy an empowered life with acceptance.







#### **COMMUNITY VALUES**

As the global CMN patient community we:

- Put the needs and interests of people affected by CMN first
- Are as inclusive as possible and foster connectivity within our growing community
- Create a strong sense of belonging where people feel supported and empowered

#### ORGANISATIONAL VALUES

As an international alliance of CMN patient organisations we are:

- Innovative in our approach and global in our outlook
- Highly collaborative and always act with integrity
- Determined to be impactful and ensure our work is of high quality
- Transparent about our actions and accountable for all that we do

## Part 2

## **Strategic Objectives**





HOW DO WE DO THIS?

# 3 Year Strategic Plan with SMART Objectives

Specific - The goal is concrete and tangible. Everyone knows what it looks like.
Measurable - The goal has an objective measure of success that everyone can understand.
Attainable - The goal is challenging, but should be achievable with the resources available.
Relevant - The goal meaningfully contributes to larger objectives like the overall mission.
Timely - The goal has a deadline or, better yet, a timeline of progress milestones.

#### Mission:

Naevus Global is an international network of patient representatives, committed to enhancing the lives of those affected by CMN. We connect and empower the patient community, channel our collective expertise, and amplify our unified voice to influence global decisions that impact our community.

## Strategic Objectives

1

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

2

CMN patient representatives will be more capable of providing input into different aspects of clinical research.



Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.







#### Mission:

Naevus Global is an international network of patient representatives, committed to enhancing the lives of those affected by CMN. We connect and empower the patient community, channel our collective expertise, and amplify our unified voice to influence global decisions that impact our community.

## Strategic Objectives

9

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

#### **Reasoning:**

Regular communications and increased collaboration between CMN patient advocates help to build a global network where patient representatives feel connected, engaged, and supported.

Increased awareness of CMN-related initiatives worldwide helps foster collaboration between member organizations.

By sharing best practices, opportunities, and strategies, representatives can better support their national efforts and expand access to vital resources for those affected by CMN.



#### 2025-2027

## Strategic Objectives

## প্র

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

#### Mission:

Naevus Global is an international network of patient representatives, committed to enhancing the lives of those affected by CMN. We connect and empower the patient community, channel our collective expertise, and amplify our unified voice to influence global decisions that impact our community.

What does this look like to you?

#### Mission:

Naevus Global is an international network of patient representatives, committed to enhancing the lives of those affected by CMN. We connect and empower the patient community, channel our collective expertise, and amplify our unified voice to influence global decisions that impact our community.

## Strategic Objectives

2

CMN patient representatives will be more capable of providing input into different aspects of clinical research.

#### **Reasoning:**

The existence of national CMN patient advocates, groups, and organizations worldwide provides an opportunity for a diverse population to provide input into all kinds of clinical research (medicinal, psychological, and otherwise), from the perspective of what is important to the patient.

Naevus Global can provide a representative voice for these patient advocates, or seek out connections with those who are knowledgeable in these fields.

In order to fulfill a future goal of being able to represent, influence, and shape the global community in research, we need to think about what steps can be taken now to prepare us to be able to do so.

#### 2025-2027

## Strategic Objectives

#### Mission:

Naevus Global is an international network of patient representatives, committed to enhancing the lives of those affected by CMN. We connect and empower the patient community, channel our collective expertise, and amplify our unified voice to influence global decisions that impact our community.

2

CMN patient representatives will be more capable of providing input into different aspects of clinical research.

What does this look like to you?

#### Mission:

Naevus Global is an international network of patient representatives, committed to enhancing the lives of those affected by CMN. We connect and empower the patient community, channel our collective expertise, and amplify our unified voice to influence global decisions that impact our community.

## Strategic Objectives



Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.



**Reasoning:** 

Many clinicians around the world are still not familiar with our rare disease. There are also currently no international guidelines on treatment or care. National guidelines have been established in a few countries, but some aspects are not in agreement between them. This is confusing for both patients and medical professionals.

A Patient Journey map was created in 2019 to better explain the many stages and possible experiences associated with a CMN or NCM diagnosis. Increased visibility of this journey, created by patients for patients, will support clinicians in becoming more knowledgeable and providing better care to their patients worldwide.

#### 2025-2027

## Strategic Objectives

## 3

Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.

#### Mission:

Naevus Global is an international network of patient representatives, committed to enhancing the lives of those affected by CMN. We connect and empower the patient community, channel our collective expertise, and amplify our unified voice to influence global decisions that impact our community.

What does this look like to you?

#### 2025-2027

## Strategic Objectives



1

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

2

CMN patient representatives will be more capable of providing input into different aspects of clinical research.



Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.



 $\rightarrow$ 



## Part 3

## **Action Plan & Key Performance Indicators**





#### **Strategic Objective**

1

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

#### **Short Term Goals**

- 1. Increase meaningful connection between CMN patient representatives globally.
- 2. Establish a platform for member knowledge, experience, communications and opportunities exchanges.

3. Coordinate joint global action to raise awareness about CMN.

## Strategic Objective:

CMN patient
representatives
globally will
feel more
empowered
and capable of
advocating on
behalf of
people with
CMN.

Short Term Goals	Key Performance Indicators (KPIs) (Tactics - What we will do to achieve the goal / How we know we will have achieved the goal)
1) Increase meaningful connection between CMN patient representatives globally.	<ul> <li>Host in-person patient representative meeting, in connection to GlobalSkin Conference (24-27 April 2025, Prague).</li> <li>Host webinar to facilitate knowledge &amp; experience exchange between CMN patient groups/representatives (Autumn 2025).</li> </ul>
2) Establish a platform for member knowledge, experience, communications and opportunities exchanges.	<ul> <li>Outline a yearly communications plan draft.</li> <li>Identify individual(s) to manage Naevus Global communications.</li> <li>Consider website update management.</li> <li>Consider social media presence and if possible, identify someone to create/manage content.</li> <li>Organise a communal calendar for upcoming CMN patient group conferences &amp; other relevant events.</li> <li>Consider a digital platform for sharing resources.</li> <li>Disseminate information about opportunities via GlobalSkin, EURORDIS, RDI (i.e. applications for funding).</li> </ul>
3) Coordinate joint global action to raise awareness about CMN.	<ul> <li>Raise awareness of Rare Disease Day resources (28 February).</li> <li>Disseminate toolkit for Global CMN Awareness Day (28 September).</li> <li>Encourage submissions of upcoming, local initiatives.</li> </ul>

#### **Strategic Objective**

2

CMN patient representatives will be more capable of providing input into different aspects of clinical research.

#### **Short Term Goals**

- 1. Connect and engage with key researchers.
- 2. Identify and raise awareness of CMN-related research opportunities.

## Strategic Objective:

CMN patient representatives will be more capable of providing input into different aspects of clinical research.

Short Term Goals	Key Performance Indicators (KPIs) (Tactics - What we will do to achieve the goal / How we know we will have achieved the goal)
1) Connect and engage with key researchers.	<ul> <li>Identify key conferences internationally where we can meet and connect with relevant researchers &amp; clinicians.</li> <li>Attend conferences/Interact with clinicians and researchers at conferences, and stay connected.</li> </ul>
2) Identify and raise awareness of CMN-related research opportunities.	<ul> <li>Gather information about current CMN-related research projects worldwide.</li> <li>Inform CMN patient advocates about patient-relevant research findings</li> </ul>

## **Strategic Objective**



Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.

#### **Short Term Goals**

1. Disseminate patient journey literature.

2. Strengthen communications with relevant clinicians.

## Strategic Objective:

Clinicians will be more aware of the challenges experienced across the **CMN Patient** Journey, and the need for international guidelines on treatment and care.

Short Term Goals	Key Performance Indicators (KPIs) (Tactics - What we will do to achieve the goal / How we know we will have achieved the goal)
1) Disseminate patient journey literature.	<ul> <li>Educate patient advocates on use of patient journey.</li> <li>Develop infographics that highlight patient challenges and current gaps in care.</li> </ul>
2) Strengthen communications with relevant clinicians.	<ul> <li>Attend or host a stand at key relevant international conference(s) to educate on and increase visibility of CMN.</li> <li>Review the current list of medical advisors on the Naevus Global website.</li> <li>Reach out to existing contacts to poll interest in future collaboration.</li> </ul>

## **Strategic Objective**

Other:
Structure and
Governance

#### **Short Term Goals**

1. Establish a working structure for the future of Naevus Global.

2. Begin researching funding opportunities.

Strategic Objective:

Structure and Governance

## **Key Performance Indicators (KPIs)** (Tactics - What we will do to achieve the goal / **Short Term Goals** How we know we will have achieved the goal) • Review, Approve & Implement 2025-27 Strategic Plan 1) Establish a • Research incorporation possibilities in various countries. working structure • Outline a first draft Governance Framework (leadership, for the future of coordinating body, roles & responsibilities, decision making Naevus Global. powers, etc.). Consider membership criteria and application process. • Publish new mission, vision, values, & strategic plan (to contacts and on website). • Begin making a list of possible funding sources based on 2) Begin researching incorporation statuses. funding opportunities. Apply for any funding that we are already eligible for.



#### **Strategic Objective**

1

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

## Short Term Goals (unchanged)

- 1. Increase meaningful connection between CMN patient representatives globally.
- 2. Establish a platform for member knowledge, experience, communications and opportunities exchanges.

3. Coordinate joint global action to raise awareness about CMN.

## Strategic Objective:

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

Short Term Goals	Key Performance Indicators (KPIs)
1) Increase meaningful connection between CMN patient representatives globally.	<ul> <li>Host in-person patient representative meeting, in connection to World Congress on Rare Skin Diseases Conference (July 2026).</li> <li>Increase number of online webinars hosted by NG, to facilitate knowledge &amp; experience exchange between CMN patient groups/representatives.</li> <li>Representative from Naevus Global attend at least 3 national CMN patient organization gatherings</li> </ul>
2) Establish a platform for member knowledge, experience, communications and opportunities exchanges.	<ul> <li>Establish a communications channel between patient representatives.</li> <li>Continue disseminating information about new opportunities (i.e. applications for funding).</li> <li>Create/update an online resource library.</li> <li>Identify individual(s) in our community who could assist with language translation for critical materials.</li> <li>Develop a general template for streamlined branding to share our network's resource materials.</li> <li>Brainstorm materials for toolkit on starting a CMN patient organisation.</li> </ul>
3) Coordinate joint global action to raise awareness about CMN.	<ul> <li>Create &amp; disseminate a CMN-specific toolkit for Rare Disease Day (28 February).</li> <li>Disseminate toolkit for Global CMN Awareness Day (28 September).</li> <li>Encourage submissions of upcoming, local initiatives.</li> </ul>

#### **Strategic Objective**

2

CMN patient representatives will be more capable of providing input into different aspects of clinical research.

#### Short Term Goals (unchanged)

- 1. Connect and engage with key researchers.
- 2. Identify and raise awareness of CMN-related research opportunities.

## Strategic Objective:

CMN patient representatives will be more capable of providing input into different aspects of clinical research.

Short Term Goals	Key Performance Indicators (KPIs)
1) Connect and engage with key researchers.	<ul> <li>Continue attending key conferences/Interact with clinicians and researchers at conferences, and stay connected.</li> <li>Conduct a research-specific survey to steer NG activities?</li> </ul>
2) Identify and raise awareness of CMN-related research opportunities.	<ul> <li>Distribute a newsletter or website blog post with updates following key congresses.</li> <li>Inform patient representatives of current research happenings.</li> <li>Brainstorm conducting a mapping exercise of existing CMN research: Make steps toward defining "interesting and relevant" medical literature from an organizational point of view, consider making a public list available.</li> </ul>

#### **Strategic Objective**



Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.

#### **Short Term Goals**

- 1. Review/update existing CMN Patient Journey and Melanoma Patient Pathway for CMN.
- 2. Disseminate patient journey literature.

3. Strengthen communications with relevant clinicians.

# Strategic Objective:

Clinicians will be more aware of the challenges experienced across the **CMN Patient** Journey, and the need for international guidelines on treatment and care.

Short Term Goals	Key Performance Indicators (KPIs)
1) Review/update existing CMN Patient Journey and Melanoma Patient Pathway for CMN.	<ul> <li>Update the CMN and Melanoma patient journeys:         Broaden to include multidisciplinary factors and patient perspective/input.     </li> </ul>
2) Disseminate patient journey literature.	<ul> <li>Develop and distribute infographics and guides that highlight patient challenges and current gaps in care.</li> <li>Gather &amp; publish case studies/personal stories to humanize the challenges faced in the CMN Patient Journey.</li> </ul>
3) Strengthen communications with relevant clinicians.	<ul> <li>Attend or host a stand at key relevant international conference(s) to educate on and increase visibility of CMN.</li> </ul>

## **Strategic Objective**

Other:
Structure and
Governance

## Short Term Goals (unchanged)

1. Establish a working structure for the future of Naevus Global.

# Strategic Objective:

Structure and Governance

Short Term Goals	Key Performance Indicators (KPIs)
1) Establish a working structure for the future of Naevus Global.	<ul> <li>Decide on legal structure &amp; incorporation.</li> <li>Fill leadership roles.</li> <li>Create an operating budget.</li> <li>Identify opportunities for revenue streams based on incorporation.</li> <li>Consider branding &amp; website updates.</li> </ul>



#### **Strategic Objective**

1

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

#### **Short Term Goals** (unchanged)

- 1. Increase meaningful connection between CMN patient representatives globally.
- 2. Establish a platform for member knowledge, experience, communications and opportunities exchanges.

3. Coordinate joint global action to raise awareness about CMN.

# Strategic Objective:

CMN patient representatives globally will feel more empowered and capable of advocating on behalf of people with CMN.

Short Term Goals	Key Performance Indicators (KPIs)
1) Increase meaningful connection between CMN patient representatives globally.	<ul> <li>Host in-person patient representative meeting, in connection to GlobalSkin Conference (Dates TBD, likely Q2 2027).</li> <li>Host quarterly online webinars to facilitate knowledge &amp; experience exchange between CMN patient groups/representatives.</li> <li>Establish a community mentorship program.</li> <li>Increase Naevus Global representation at national CMN patient organization gatherings.</li> </ul>
2) Establish a platform for member knowledge, experience, communications and opportunities exchanges.	<ul> <li>Create a submission process for materials to be edited, created, and/or disseminated amongst CMN patient groups.</li> <li>Identify and share information about opportunities from new sources (i.e. funding, research).</li> </ul>
3) Coordinate joint global action to raise awareness about CMN.	<ul> <li>Disseminate toolkit for Rare Disease Day (28 February).</li> <li>Disseminate toolkit for Global CMN Awareness Day (28 September).</li> <li>Encourage submissions of upcoming, local initiatives.</li> <li>Consider one additional joint awareness action.</li> </ul>

#### **Strategic Objective**

2

CMN patient representatives will be more capable of providing input into different aspects of clinical research.

#### **Short Term Goals**

1. Conduct a mapping exercise of existing CMN research and identify key gaps.

## Strategic Objective:

CMN patient representatives will be more capable of providing input into different aspects of clinical research.

## **Short Term Goals Key Performance Indicators (KPIs)** Ask patient experts to compile local research findings. Host a meeting with researchers, clinicians, and other relevant stakeholders to discuss key gaps and consensus. • Identify criteria for judging relevance and importance of 1) Conduct a existing and future research. mapping exercise of Categorise existing research materials, using expert existing CMN expertise. research and • Compile available research into a central database. identify key gaps. • Update the list of the scientific advisory committee section of the Naevus Global website (start by reviewing what we call it and reach out to those on the list for updated contacts).

#### **Strategic Objective**



Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.

#### **Short Term Goals**

1. Disseminate updated patient journey literature.

2. Strengthen communications with relevant clinicians.

# Strategic Objective:

Clinicians will be more aware of the challenges experienced across the **CMN Patient** Journey, and the need for international guidelines on treatment and care.

Short Term Goals	Key Performance Indicators (KPIs)
1) Disseminate updated patient journey literature.	<ul> <li>Seek opportunities to educate medical and healthcare professionals about the updated CMN patient journey, such as organizing webinars, workshops, or presentations for clinicians on CMN-specific challenges, including multi-disciplinary approaches to care.</li> </ul>
3) Strengthen communications with relevant clinicians.	Attend or host a stand at key relevant international conference(s) to educate on and increase visibility of CMN.

## **Strategic Objective**

Other:
Structure and
Governance

#### **Short Term Goals**

1. Grow a sustainable working structure for the organisation.

# Strategic Objective:

Structure and Governance

Short Term Goals	Key Performance Indicators (KPIs)
1) Grow a sustainable working structure for the organisation.	<ul> <li>Grow the leadership team.</li> <li>Initiate formal member registration process.</li> <li>Identify any tools or resources needed to successfully carry out this structure (i.e. programs, softwares, websites, workflows).</li> <li>Draft a succession plan.</li> </ul>

# Part 4

## **Summary & Future Planning**

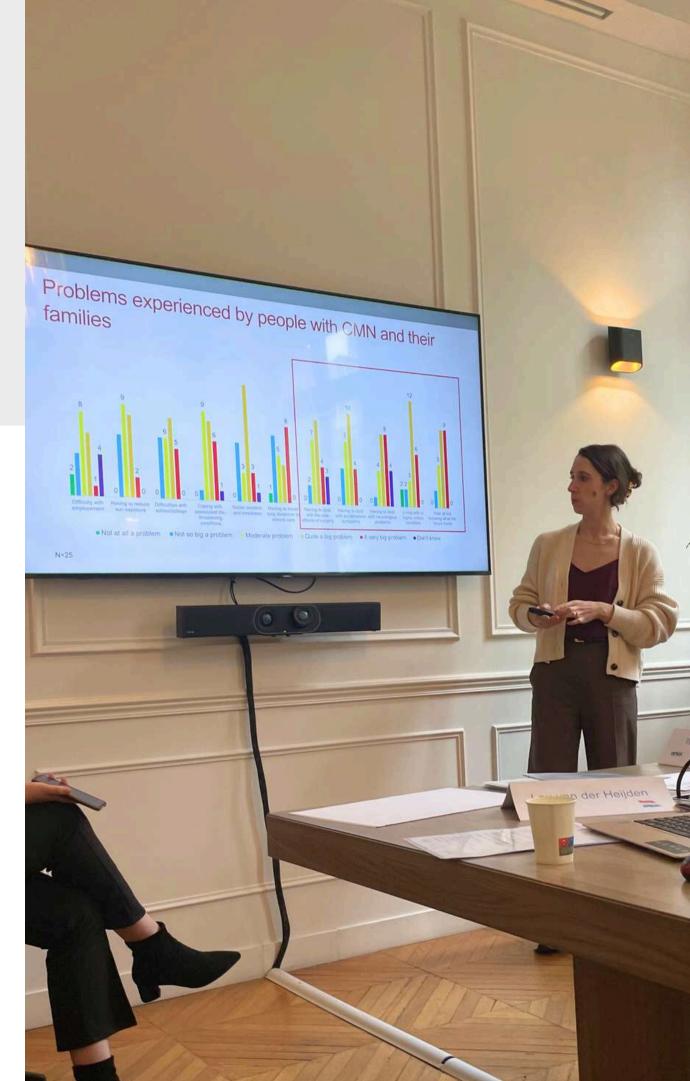
	Strategic Objective	Short Term Goals	Key Performance Indicators (KPIs)
Overview (reflects current capacity)	CMN patient representatives globally will feel more empowered and capable of advocating on behalf of their communities.	Increase meaningful connection between CMN patient representatives globally.	<ul> <li>Host in-person patient representative meeting, in connection to GlobalSkin Conference (24-27 April 2025, Prague).</li> <li>Host webinar to facilitate knowledge &amp; experience exchange between CMN patient groups/representatives (Autumn 2025).</li> </ul>
		Establish a platform for member knowledge, experience, communications and opportunities exchanges.	<ul> <li>Outline a yearly communications plan draft.</li> <li>Identify individual(s) to manage Naevus Global communications.</li> <li>Consider website update management.</li> <li>Consider social media presence and if possible, identify someone to create/manage content.</li> <li>Organise a communal calendar for upcoming CMN patient group conferences &amp; other relevant events.</li> <li>Consider a digital platform for sharing resources.</li> <li>Disseminate information about opportunities via GlobalSkin, EURORDIS, RDI (i.e. applications for funding).</li> </ul>
		Coordinate joint global action to raise awareness about CMN.	<ul> <li>Raise awareness of Rare Disease Day resources (28 February).</li> <li>Disseminate toolkit for Global CMN Awareness Day (28 September).</li> <li>Encourage submissions of upcoming, local initiatives.</li> </ul>
	CMN patient representatives will be more capable of providing input into different aspects of clinical research.	Connect and engage with key researchers.	<ul> <li>Identify key conferences internationally where we can meet and connect with relevant researchers &amp; clinicians.</li> <li>Attend conferences/Interact with clinicians and researchers at conferences, and stay connected.</li> </ul>
		Identify and raise awareness of CMN-related research opportunities.	<ul> <li>Research current CMN-related research projects</li> <li>Inform CMN patient advocates about patient-relevant research findings</li> </ul>
	Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.	Disseminate patient journey literature.	<ul> <li>Educate patient advocates on use of patient journey.</li> <li>Develop infographics that highlight patient challenges and current gaps in care.</li> </ul>
		Strengthen communications with relevant clinicians.	<ul> <li>Attend or host a stand at key relevant international conference(s) to educate on and increase visibility of CMN.</li> <li>Review the current list of medical advisors on the Naevus Global website.</li> <li>Reach out to existing contacts to poll interest in future collaboration.</li> </ul>
	Other: Structure and Governance	Establish a working structure for the future of Naevus Global.	<ul> <li>Review, Approve &amp; Implement 2025-27 Strategic Plan</li> <li>Research incorporation possibilities in various countries.</li> <li>Outline a first draft Governance Framework (leadership, co-ordinating body, roles &amp; responsibilities, decision making powers, etc.).</li> <li>Consider membership criteria and application process.</li> <li>Publish new mission, vision, values, &amp; strategic plan (to contacts and on website).</li> </ul>
		Begin researching funding opportunities.	<ul> <li>Begin making a list of possible funding sources based on incorporation statuses.</li> <li>Apply for any funding that we are already eligible for.</li> </ul>

	Strategic Objective	Short Term Goals	Key Performance Indicators (KPIs)
2 0 2 6	CMN patient representatives globally will feel more empowered and capable of advocating on behalf of their communities.	Increase meaningful connection between CMN patient representatives globally.	<ul> <li>Host in-person patient representative meeting, in connection to World Congress on Rare Skin Diseases Conference (Date TBD, likely in Summer 2026).</li> <li>Increase number of online webinars hosted by NG, to facilitate knowledge &amp; experience exchange between CMN patient groups/representatives.</li> <li>Representative from Naevus Global attend at least 3 national CMN patient organization gatherings</li> </ul>
		Establish a platform for member knowledge, experience, communications and opportunities exchanges.	<ul> <li>Establish a communications channel between patient representatives.</li> <li>Continue disseminating information about new opportunities (i.e. applications for funding).</li> <li>Create/update an online resource library.</li> <li>Identify individual(s) in our community who could assist with language translation for critical materials.</li> <li>Develop a general template for streamlined branding to share our network's resource materials.</li> <li>Brainstorm materials for toolkit on starting a CMN patient organisation.</li> </ul>
		Coordinate joint global action to raise awareness about CMN.	<ul> <li>Create &amp; disseminate a CMN-specific toolkit for Rare Disease Day (28 February).</li> <li>Disseminate toolkit for Global CMN Awareness Day (28 September).</li> <li>Encourage submissions of upcoming, local initiatives.</li> </ul>
	CMN patient representatives will be more capable of providing input into different aspects of clinical research.	Connect and engage with key researchers.	<ul> <li>Continue attending key conferences/Interact with clinicians and researchers at conferences, and stay connected.</li> <li>Conduct a research-specific survey to steer NG activities?</li> </ul>
		Identify and raise awareness of CMN-related research opportunities.	<ul> <li>Distribute a newsletter or website blog post with updates following key congresses.</li> <li>Inform patient representatives of current research happenings.</li> <li>Brainstorm conducting a mapping exercise of existing CMN research: Make steps toward defining "interesting and relevant" medical literature from an organizational point of view, consider making a public list available.</li> </ul>
Overview	Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.	Review/update existing CMN Patient Journey and Melanoma Patient Pathway for CMN.	• Update the CMN and Melanoma patient journeys: Broaden to include multidisciplinary factors and patient perspective/input.
		Disseminate patient journey literature.	<ul> <li>Develop and distribute infographics and guides that highlight patient challenges and current gaps in care.</li> <li>Gather &amp; publish case studies/personal stories to humanize the challenges faced in the CMN Patient Journey.</li> </ul>
		Strengthen communications with relevant clinicians.	• Attend or host a stand at key relevant international conference(s) to educate on and increase visibility of CMN.
	Other: Structure and Governance	Establish a working structure for the future of Naevus Global.	<ul> <li>Decide on legal structure &amp; incorporation.</li> <li>Fill leadership roles.</li> <li>Create an operating budget.</li> <li>Identify opportunities for revenue streams based on incorporation.</li> <li>Consider branding &amp; website updates</li> </ul>

	Strategic Objective	Short Term Goals	Key Performance Indicators (KPIs)
2 7	CMN patient representatives globally will feel more empowered and capable of advocating on behalf of their communities.	Increase meaningful connection between CMN patient representatives globally.	<ul> <li>Host in-person patient representative meeting, in connection to GlobalSkin Conference (Dates TBD, likely Q2 2027).</li> <li>Host quarterly online webinars to facilitate knowledge &amp; experience exchange between CMN patient groups/representatives.</li> <li>Establish a community mentorship program.</li> <li>Increase Naevus Global representation at national CMN patient organization gatherings.</li> </ul>
		Establish a platform for member knowledge, experience, communications and opportunities exchanges.	<ul> <li>Create a submission process for materials to be edited, created, and/or disseminated amongst CMN patient groups.</li> <li>Identify and share information about opportunities from new sources (i.e. funding, research).</li> </ul>
		Coordinate joint global action to raise awareness about CMN.	<ul> <li>Disseminate toolkit for Rare Disease Day (28 February).</li> <li>Disseminate toolkit for Global CMN Awareness Day (28 September).</li> <li>Encourage submissions of upcoming, local initiatives.</li> <li>Consider one additional joint awareness action.</li> </ul>
	CMN patient representatives will be more capable of providing input into different aspects of clinical research.	Conduct a mapping exercise of existing CMN research and identify key gaps.	<ul> <li>Ask patient experts to compile local research findings.</li> <li>Host a meeting with researchers, clinicians, and other relevant stakeholders to discuss key gaps and consensus.</li> <li>Identify criteria for judging relevance and importance of existing and future research.</li> <li>Categorise existing research materials, using expert expertise.</li> <li>Compile available research into a central database.</li> <li>Update the list of the scientific advisory committee section of the Naevus Global website (start by reviewing what we call it and reach out to those on the list for updated contacts).</li> </ul>
	Clinicians will be more aware of the challenges experienced across the CMN Patient Journey, and the need for international guidelines on treatment and care.	Disseminate updated patient journey literature.	<ul> <li>Create and share new infographics about the updated patient journey via social media.</li> <li>Seek opportunities to educate medical and healthcare professionals about the updated CMN patient journey, such as organizing webinars, workshops, or presentations for clinicians on CMN-specific challenges, including multi-disciplinary approaches to care.</li> </ul>
		Strengthen communications with relevant clinicians.	• Attend or host a stand at key relevant international conference(s) to educate on and increase visibility of CMN.
	Other: Structure and Governance	Grow a sustainable working structure for the organisation.	<ul> <li>Grow the leadership team.</li> <li>Initiate formal member registration process.</li> <li>Identify any tools or resources needed to successfully carry out this structure (i.e. programs, softwares, websites, workflows).</li> <li>Draft a succession plan.</li> </ul>

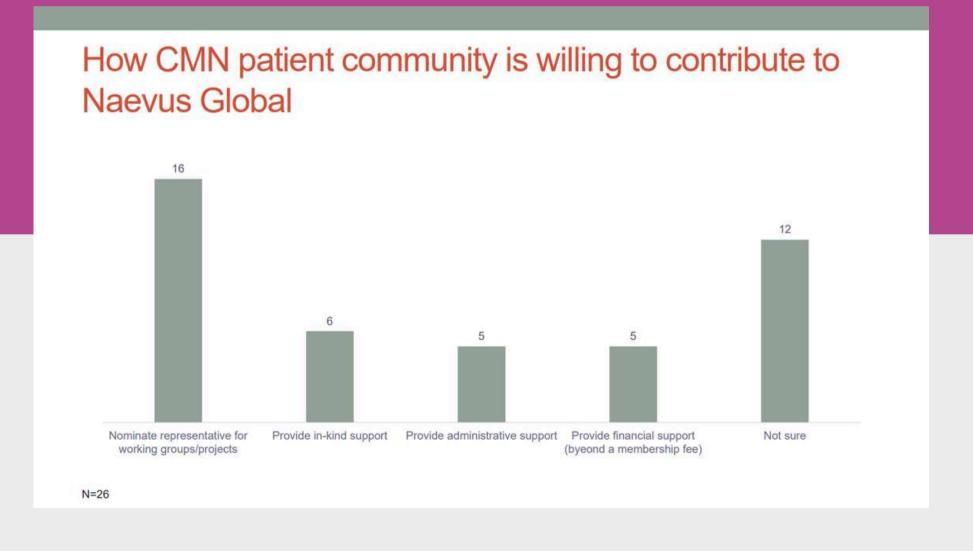
# Some Ideas for Beyond 2027

- Build a scientific/medical advisory council or committee.
- Compile available research into a central database.
- Recruit a researcher to support this process.
- Identifying gaps in research and follow up with next steps (including fundings needs, etc)
- Host an in-person researchers meeting in conjunction with WCRSD
   2028 (or other conference they are likely to already be attending)
- Host a global meeting for CMN clinicians/medical professionals





# We need your help!



# THANKYOU

