

## Report on 2020 Worldwide Survey

**Authors:**

Antoine Gliksohn  
Michael McGowan

**Contributors:**

Carolin Schroeder  
Elizabeth Beales  
Julio Garcia



# Report on 2020 Worldwide Survey - Executive Summary

[albinismalliance.pilot@gmail.com](mailto:albinismalliance.pilot@gmail.com)

**In June 2020, the Global Albinism Alliance Pilot launched a survey to consult albinism organizations from around the world.**

**This document presents the most prominent content of the Survey Report published in May 2021 as determined by the pilot team.**



**Global  
Albinism  
Alliance**

# Links to Full Reports

Readers should refer to the full report for details on areas of most interest to them:

- [English](#)
- [French](#)
- [Portuguese](#)
- [Spanish](#)



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# Survey Goals, Population & Response Rate



## Survey Goals

**Update and enrich a worldwide database** with contact information for albinism organizations from around the world.

**Gather information** on what albinism groups around the world would like to see in a permanent alliance.

**Get an overview** of the nature, characteristics and commonalities of **albinism organizations around the world.**

**Document challenges** faced by persons with albinism around the world.



# Population & Response Rate

- The Global Albinism Alliance (GAA) had an initial list of 247 albinism organizations covering 90 countries when the survey was launched.
- 184 groups among them could be contacted via email.
- 5 groups heard about the survey through other means of communication.
- **145 complete survey responses** were received in total.
- 129 responses came from organizations already listed in the GAA database.
- 16 responses came from organizations that the GAA didn't know of previously.
- A **68% response rate** was confirmed among the known organizations, considering the groups that could be reached directly.

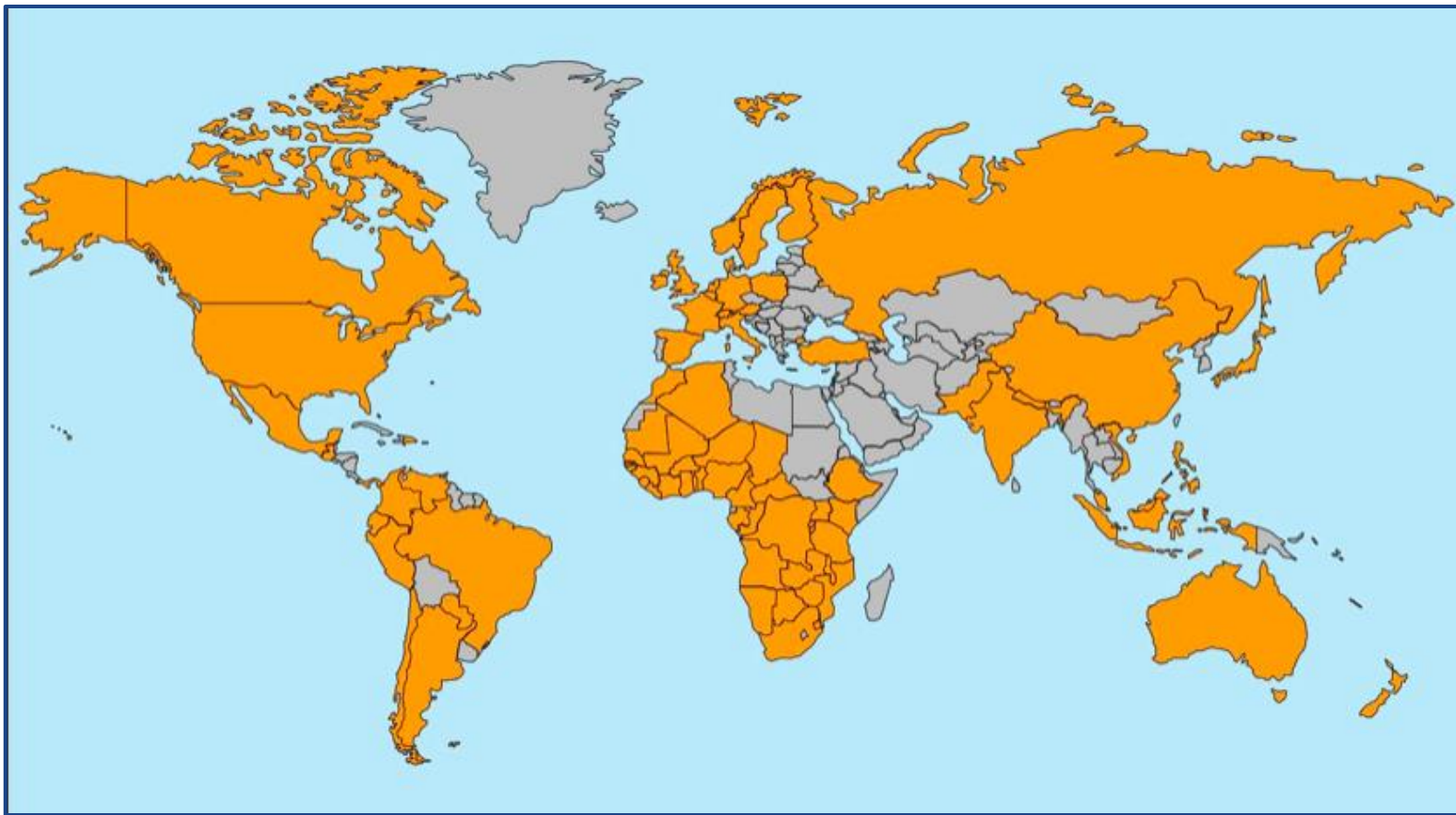


# Survey Results

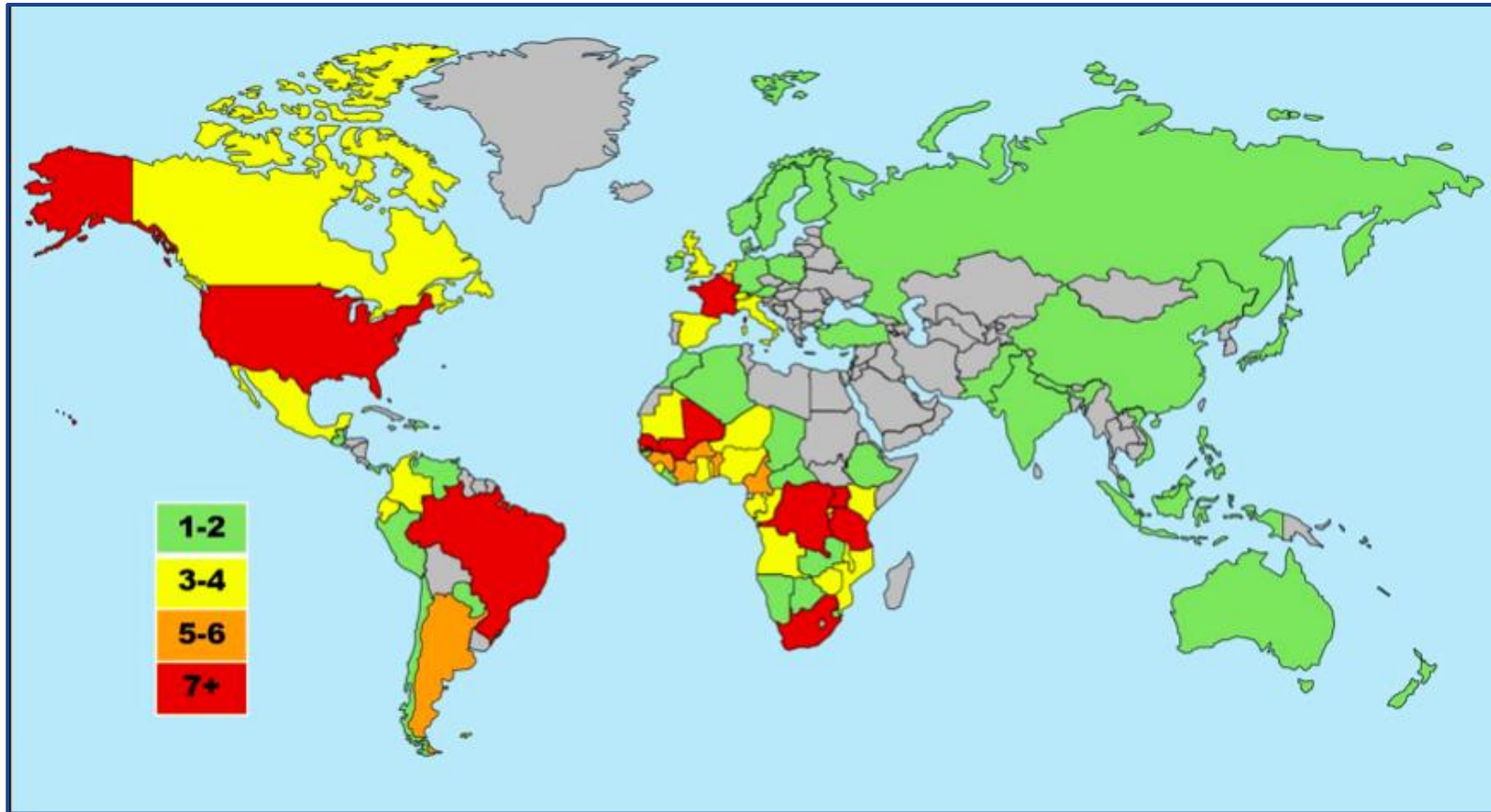




# Countries where Organizations who Participated in the Survey are Operating



# Number of Organizations Operating in each Country covered by the Survey

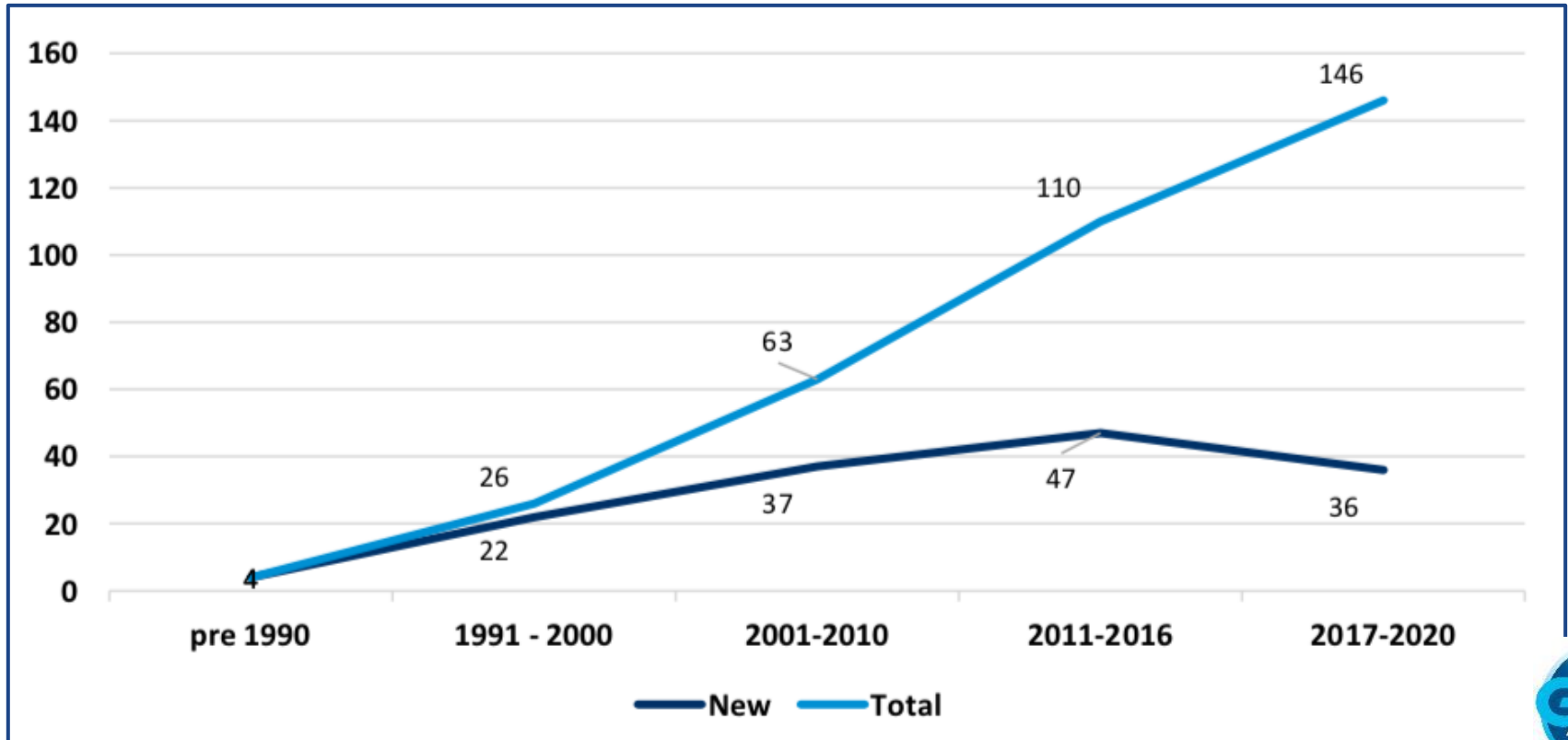


# Areas of Operation - Observations

- Albinism organizations who participated in the survey operate in **80 countries** on **6 continents**.
- **Areas currently NOT covered or little covered** by albinism organizations:
  - Southern & Eastern Europe
  - Pacific (Melanesia, Micronesia and Polynesia)
  - Central America
  - Central Asia
  - North Africa & Western Asia
  - Southern, Eastern & South-eastern Asia
- Some countries (e.g. DRC) have multiple national organizations operating at the same time.



# Number of Albinism Organizations by Length of Time in Operation



# Growth of Operations Over Time - Main Observations

1980s - Present

**Over the past 40 years, there has been a steady increase in albinism organizations worldwide.**

Since 2000

**Rapid growth occurred in the 2000's, and the number of albinism organizations has more than doubled since 2010.**

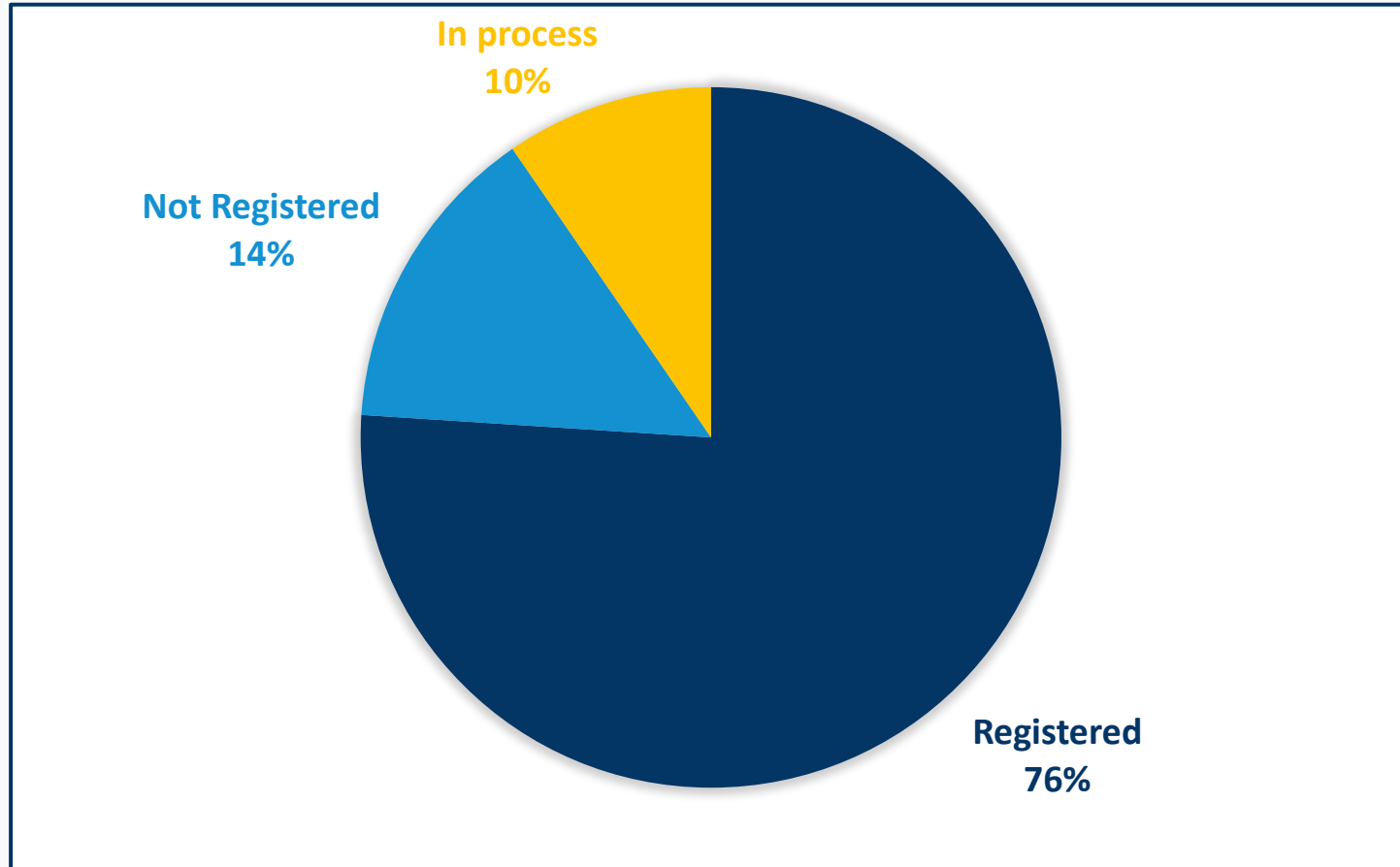
*Since 2017*

**36 more albinism organizations have been operating since 2017.**

From this data it is reasonable to conclude that the number of new albinism organizations will continue to grow.



# Breakdown of Albinism Organizations by Registration Status

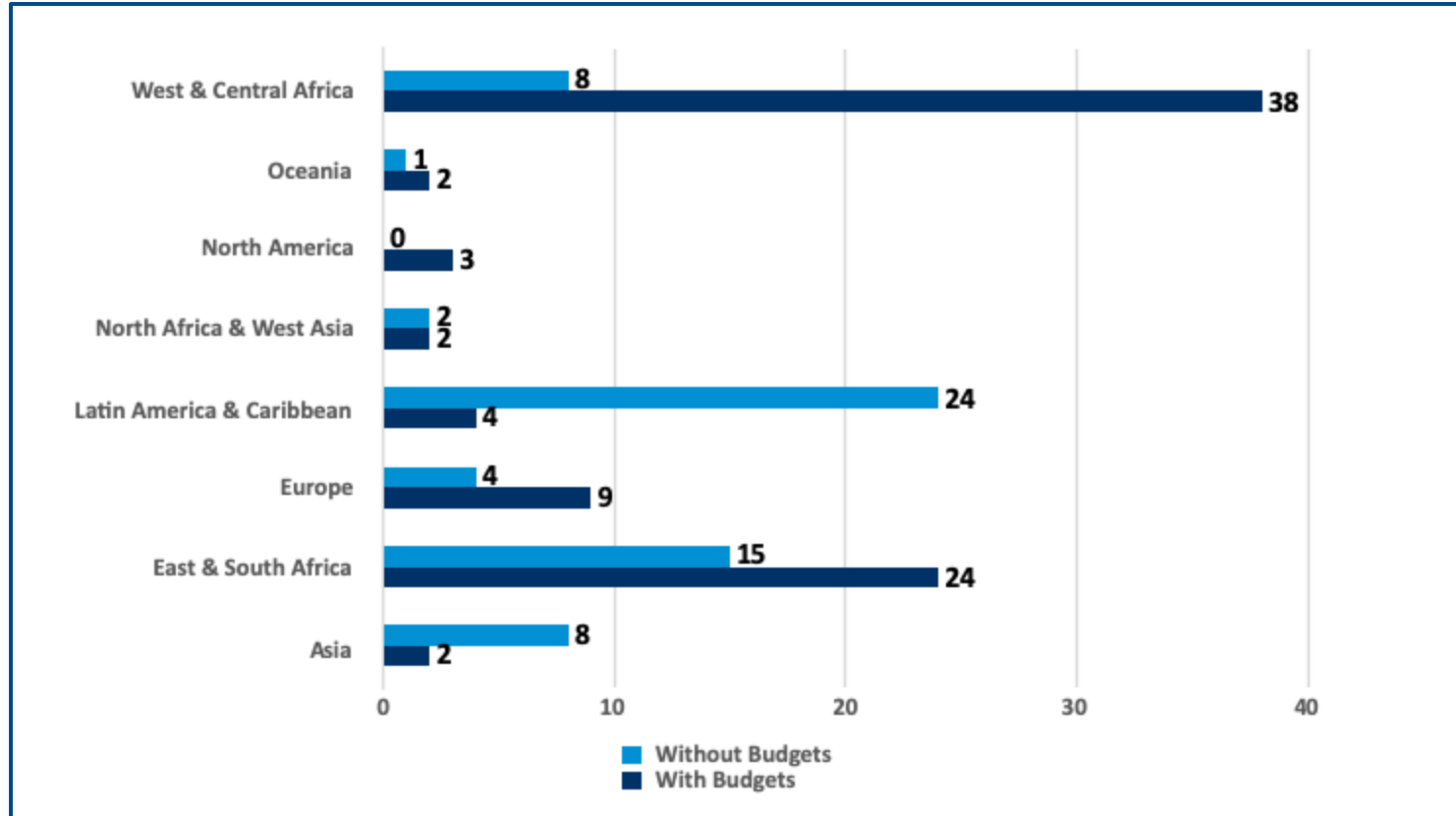


# Registration Status - Main Observations

- 146 survey respondents answered the question on their organization's registration status;
  - **111 groups are registered (about 75%)**
  - **21 groups are not registered**
  - **14 are in the process of registering**
- It is reasonable to conclude that the registration process greatly differs from one country to another, and includes diverse constraints such as registration fees. These various factors most probably contribute to explaining the observed data, at least partially.



# Breakdown of Albinism Organizations With and Without Budgets by Region





# Budgets - Main Observations

**84 organizations** out of **145** shared their latest annual operating budget or an average of their latest annual budgets.

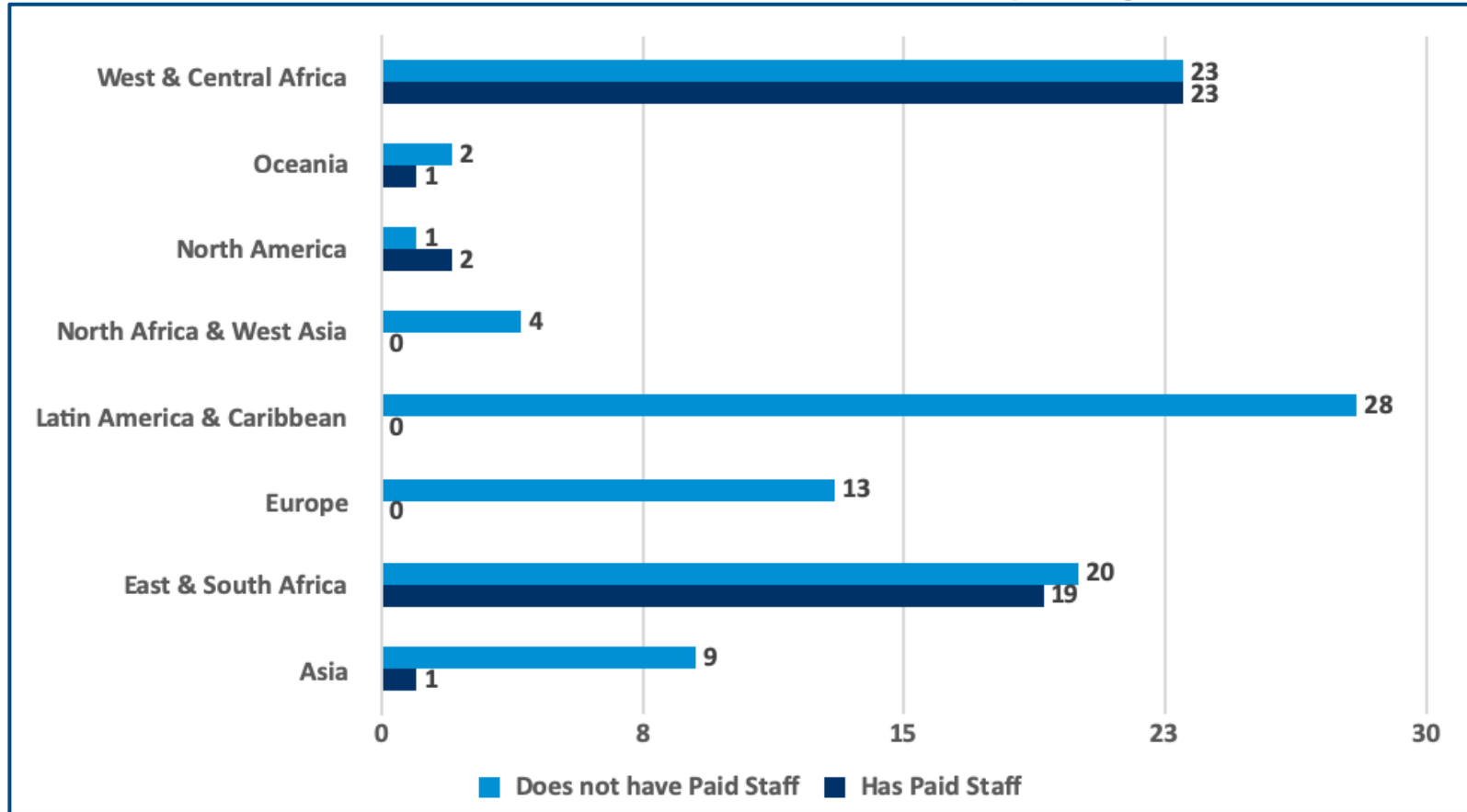
- **22** organizations have a budget **over \$95,000**
- **17** organizations have a budget **between \$40,000 and \$95,000**
- **18** organizations have a budget **between \$15,000 and \$40,000**
- **16** organizations have a budget **between \$5,000 and \$15,000**
- **11** organizations have a budget **below \$5,000**

> **34** out of 39 **organizations with an annual budget of over \$40 000 are operating in Western, Central, Eastern or Southern Africa**

\* There seems to be a correlation between the number of years of operation and the amount of the annual operating budget.



# Breakdown of Albinism Organizations With and Without Paid Staff by Region



# Staffing: Main Observations

- **46** out of the 145 survey respondents **have paid staff**
- **42 of them are operating in Africa**, with the exception of North Africa.
- **6** out of these 42 groups **have their headquarters in Europe or in North America**.
- The other 4 organizations with paid staff are operating in the following countries: USA, Canada, China, and Fiji.
- **All other albinism organizations around the world rely exclusively on volunteers** to sustain their operations



# Future Alliance Considerations

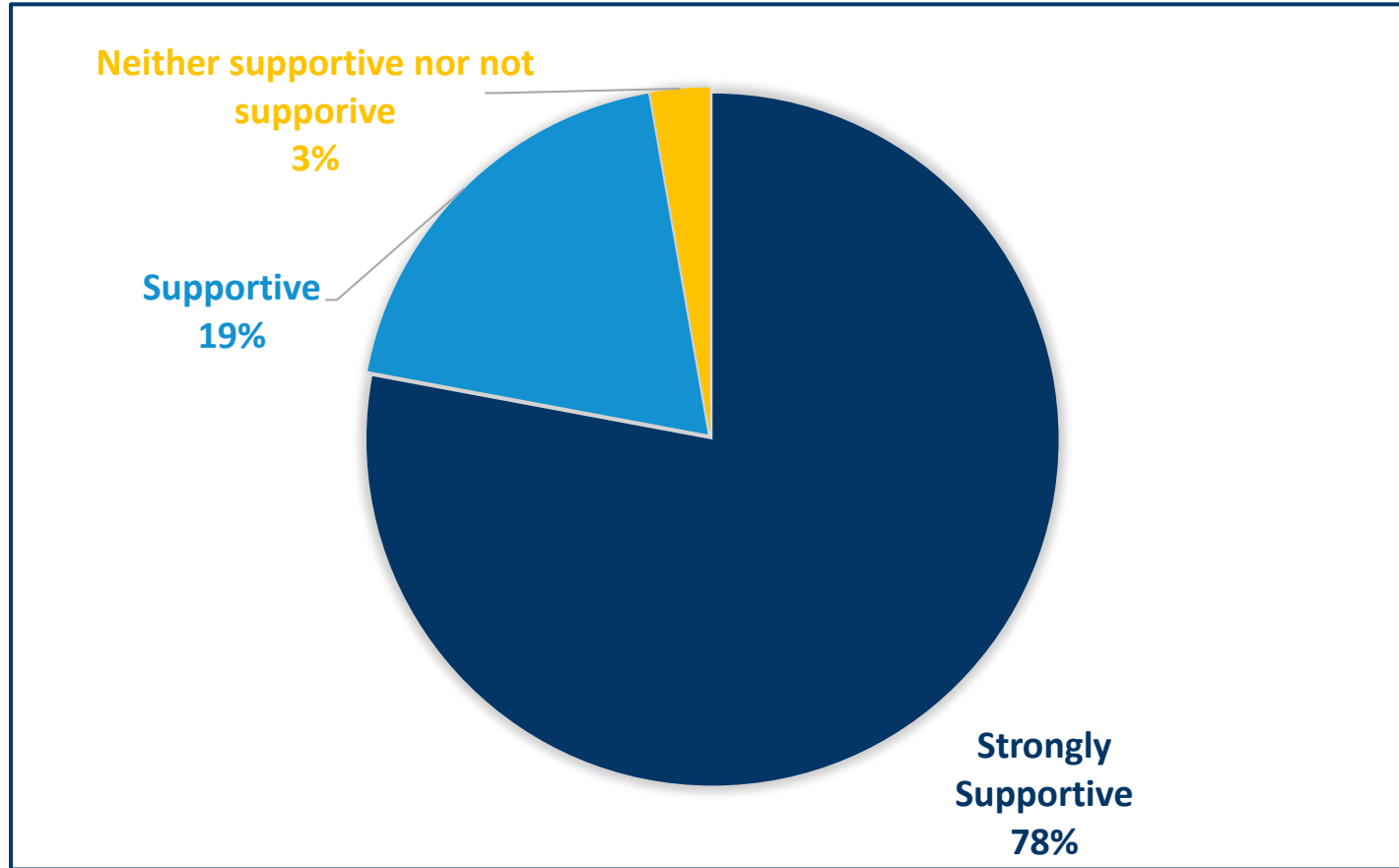


# Accessibility

- The Global Albinism Alliance must operate a way that ensures all voices are heard and acknowledged.
- All activities and actions of the alliance must be as accessible as possible, regardless of language and/or culture.
- As such, the worldwide survey sought to determine a realistic number of languages that could effectively be used by the Global Albinism Alliance.
- Survey results indicate that **a Global Albinism Alliance operating in English, French, Spanish and Portuguese would effectively reach the vast majority of albinism organizations** currently operating in the world.



# Support of Respondents of the Development of a Formal International Alliance on Albinism



# Degree of Support from Survey Respondents

- **97% of respondents - an overwhelming majority - expressed their support for a global albinism alliance.**
- **0% of respondents opposed the formation of the alliance.**
- The strong overall support received from the survey respondents gives the GAA Pilot Team the required legitimacy to further work on defining the missions of this alliance.
- It is worth noting that respondents were not given any description of the potential future missions of the alliance.
- It is, therefore, reasonable to assume that the concept of a global alliance varies somewhat across respondents.



# Potential Functions of the Alliance

A list of 11 potential functions of the future alliance was submitted to the survey respondents who were asked to select what they believed are the 3 most important.

- **All 11 potential functions received some level of support**, and none were seen to be irrelevant.
- **62%** of all survey respondents **selected one or both of the following functions:**
  - **Promoting and spreading accurate information on albinism worldwide**
  - **Developing and implementing programs of public awareness and education on albinism**
- These 2 functions cover very similar concepts. Developing education and public awareness efforts is effective towards spreading accurate information. If considered as the same function, they are the most supported one by survey respondents.





# Potential Functions of the Alliance

- **57%** of all survey respondents **selected the function:**  
**“Developing a global strategy and action plan on albinism”**.
- However, no definition of a strategy and global action plan was given. The lack of a detailed definition of this potential function of the future alliance can lead to many different interpretations.



## 11 Potential Functions of the Global Albinism Alliance

|   |  |   |
|---|--|---|
| Develop a global strategy and action plan on albinism.  |  | Develop and implement programs of public awareness and education on albinism. |
| Facilitate collaboration among albinism groups and other stakeholders working on albinism.  | Facilitate knowledge and skill development of albinism groups worldwide. | Promote research on albinism and human rights.                                |
| Promote the work of albinism groups around the world.   | Promote research on albinism and life science (medical research).        | Support the founding and development of new national albinism groups.         |
| Support the founding of new regional albinism groups as well as the implementation of regional plans and initiatives on albinism. | Promote research on albinism and social science.                         | Promote and spread accurate information on albinism worldwide.                |



# Challenges that People with Albinism Face

Multiple challenges that affect the quality of life for persons with albinism, or prevent them from exercising their human rights were identified in the responses:

- Sectoral challenges covering various aspects of life such as health, education, and employment
- Overlapping or multisectoral challenges, such as exclusion, discrimination and the lack of information and awareness on albinism
- Gender-specific challenges are observed in many responses
- Cause-and-effect patterns have been noted across responses
- **The general lack of information on albinism appears to be an underlying factor for several chains of consequent negative impacts on the quality of life and human rights enjoyment for people with albinism.**



# Cause and Effects Patterns of Challenges Faced by People with Albinism

## Cause

Lack of understanding/  
prevalence of harmful  
oral histories



**Effect:** discrimination,  
persecution, gender-  
based violence, ritual  
killings

## Cause

Lack of information  
on albinism/ /lack of  
adaptation in school  
and the workplace



**Effect:** unemployment  
or inadequate  
working/schooling  
conditions

## Cause

discrimination/  
lack of rehabilitation  
and psychosocial  
support



**Effect:** mental  
health impairment /  
lack of self esteem



# Key Observations and Recommendations



# Organizational differences

|   |                               |                      |
|---|-------------------------------|----------------------|
| <b>The leaders of the future Alliance must consider that member organizations will differ by:</b> | Type                          | Mission              |
| Registration status   | Budget                        | Staffing             |
| Experience  | Stage of development          | Organizational needs |
| Capacity to dedicate time to participate in the activities of the future Alliance                 | Human and financial resources | Cultural contexts    |



# Recommendations

With the noted diverse organizational differences, the future alliance should:

- facilitate programs that provide albinism organizations with tools to become more sustainable.
- facilitate information sharing between organizations
- become the world's foremost credible source for information related to albinism.
- raise awareness about albinism, combat myths and misconceptions, and fight stigma, as necessary first steps to address the wide range of challenges faced by people with albinism.



# Conclusion





- **The data compiled via the worldwide survey is the most comprehensive description of albinism organizations ever done.**
- **There is strong support for the creation of a Global Albinism Alliance.**  
The unanimous vote of the delegates to the Paris meeting to embark on a pilot to form a Global Alliance is strongly supported by the worldwide albinism community, with 97% of survey respondents saying that they either support or strongly support the development of such an alliance.
- The rapid increase in the number of albinism organizations starting operations recently and the total number of existing organizations around the world show conclusively that **the activity of the global albinism community is growing and not diminishing.**
- The data collected in the survey supports the proposition that **this is an appropriate time to form a global alliance.**



- The future alliance will need to figure out what its mission will be. This decision will need to consider how the alliance will support types of groups including local, national, and regional organizations as well organizations that do not fit into these categories.
- **The varying degrees and severity of challenges faced by persons with albinism around the world will make it difficult for the future alliance to prioritize goals.**
- **The challenge for the future alliance will be** to carefully select the functions it will perform, to set priorities for the selected functions and **to find the resources to carry out what is likely to be an extensive range of functions.**

