



International Pediatric Transplant Association Strategic Planning 2020-23: Final Report

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A Message from the IPTA Executive Council

Spring 2020

Dear Colleagues and Friends:

Little needs to be said regarding the upheaval we're facing as we respond to the threat of COVID-19. We hope that you, your family and your colleagues are safe and healthy.

One thing is clear – we will look back on these times and mark time as either “before” or “after” the events of these past weeks. The planning process that led to this document certainly comes from a time “before”.

And still, with so much in flux, we look forward, and we plan for the future of our Association.

Much remains uncertain: the duration and intensity of shut-downs, the impact on the care providers and systems which support and sustain our communities, and most importantly, the health and safety of children eligible for or living with a transplant.

Despite these uncertainties we are looking forward to preparing for the future of our Association. We remain committed to our members and those they serve. For all of us, local demands will take precedent in the weeks and months to come. But our Association will still stand on the other side of this unfortunate situation, and the direction outlined by our members in this report will remain as relevant as ever.

We will continue to represent and work diligently with you in the weeks and months to come to advance the cause of pediatric transplantation, and we are proud to present our IPTA Strategic Plan to you for 2020-23.

Sincerely Yours:

IPTA Executive Committee.

Anne Dipchand, Past President, IPTA Strategic Plan Lead

Mignon McCulloch, President

Carlos Esquivel, President Elect

Lars Pape, Secretary-Treasurer

Introduction

In February 2019 IPTA began a strategic planning process for the next three years (2020-23).

The purpose of the planning process was to engage IPTA members setting the strategic direction for IPTA for the next three years (2020-23).

Objectives were to:

1. **Consult with** IPTA members and selected stakeholders
2. **Develop focused priorities** to focus and guide IPTA's work 2020-23.
3. **Increase IPTA member engagement and value; Grow the membership.**

The planning process was led by the IPTA Executive reporting to IPTA Council, with the support of an external consulting group.

Collaboration and membership priorities are an important focus for IPTA. An extensive consultation was conducted as part of planning, involving in-person focus groups at the Vancouver Congress (May 2019), an online membership survey, and telephone interviews with identified leaders in the field from around the world. Consultation results were synthesized and presented for consideration and further development by the IPTA Council at their February 2020 Council Meeting and Strategic Planning session.

From membership identified areas, Council members developed potential projects for IPTA, estimating the time, resources, and overall effort necessary to complete each one. These were further discussed and prioritized, resulting in the five projects outlined further in this report.

Membership and Available Resources

IPTA is driven by the passion and commitment of its membership, a multi-disciplinary group of people working together to contribute to pediatric transplantation worldwide. This community is small and diverse, with strong representation across the transplant team from allied health (35% of IPTA membership) to physicians and surgeons. This range of perspectives and professions is a key source of strength for IPTA: for many members IPTA is the home of professional collaboration.

While changing over time, most IPTA members come from North America, Europe, Australia and New Zealand. Although members are few from Asia, Latin America, Africa and other parts of the world, they also call IPTA their home. Expanding the reach of IPTA internationally is a key goal for planning and the resulting projects.

Committees staffed by volunteers are used to advance IPTA's work. Given this, planning was based on the assumption that success would only come through a structured approach to projects and priorities. The projects chosen are detailed in this document and will be the primary focus for the Association (including Congress) for the next several years.

IPTA 2020-23: Strategic Projects

Using the themes identified by IPTA members through the planning consultation process, IPTA Council selected five strategic projects using the following guidelines:

1. Projects need to be completed during the next three years, i.e., 2020-23
2. Council members will prioritize projects and theme areas according to:
 - a. Resources required (time/human/financial), and
 - b. Overall feasibility.

The projects selected are:

- A. Guideline Cataloguing and Development
- B. Building Connections; Expanding the Membership
- C. Strengthening Congress
- D. International Advocacy
- E. Education.

A note on Allied Health

35% of the IPTA members come from Allied Health professions. These members are highly engaged and supported by an active Allied Health Committee. The IPTA Governing council elected to keep existing and future projects specific to Allied Health separate and under the umbrella of the Allied Health Committee; the participation of Allied Health members is assumed in the five priorities selected. Current IPTA work in Allied health includes:

- Defining the international prevalence and diversity of clinical, research and teaching practice of AH team members, including models of care
- Advocating for the multi-disciplinary team approach to care, and in particular its' relationship to optimal patient outcomes
- Developing professional practice guidelines for AH team members to inform newer/lower resourced centres with standards of practice
- Connecting IPTA to local leaders in international programs
- Using technology and social media to build and strengthen partnership and mentorship opportunities.

Further details on the five selected projects follow.

A. Guideline Cataloguing and Development

Although there is ongoing work in this area, the gaps, type and number of guidelines and/or position statements related to pediatric transplantation are unknown. This project will categorize existing publications and create an online catalogue accessible to IPTA members, identify areas for future guideline/position statement development, and create an IPTA infrastructure for guideline/position statement development in the process.

Action steps are:

1. **Build** IPTA rules for guideline/position statement development
2. **Identify** existing guidelines and position statements and catalogue them, making them available online for IPTA members
3. **Identify** gaps with membership input
4. **Create** organ specific writing groups; coordinate with existing committees and other societies
5. **Develop** new guidelines/position statements.

B. Building Connections; Expanding the Membership

Increasing the numbers and geographic breadth of IPTA's membership was a major theme during the membership consultation. IPTA Members identified opportunities to collaborate with existing local/regional entities as well as other single organ societies. This area focuses on targeted outreach in the Pacific Rim, Central and South America, and Africa to build exchanges and engagement with others working in pediatric transplantation.

Action steps are:

1. **Identify** APEC (Asia-Pacific Economic Cooperation) leaders and transplant units
2. **Identify** regional meetings and programs with potential for pediatric input
3. **Develop** a report for the journal, Pediatric Transplantation, regarding country/region transplantation programs
4. **Develop** a template for educational exchanges through existing regional meetings and single organ societies.

C. Strengthening Congress

Networking with peers and being exposed to the latest scientific advancements have always been important features of the appeal of IPTA. Members identified the collegial appeal of Congress and opportunities to present their work to an international audience of peers as one of the most important valuable benefits to membership. This project aims to use past congress planning successes as a template for the future.

Action steps are:

1. **Gather** planning and decision-making Guidelines for congress; **Develop** a formal set of planning guidelines based on existing materials.
2. **Identify** future opportunities, including interactive formats, emerging leaders, greater regional representation, and partnerships with other societies and sub-specialty groups
3. **Explore** lower cost options for congress

4. **Explore** the feasibility of holding special IPTA meetings in off-congress years.

D. International Advocacy

International advocacy is a new direction for IPTA and represents a new opportunity to represent members and the patients and families they serve. This project intends to advance the cause of the children and youth who stand to benefit from a transplant, worldwide.

Action steps are:

1. **Survey** the existing landscape of allocation for pediatric transplantation
2. **Define** an ethical mandate for deceased organ allocation to pediatric recipients
3. **Determine** the optimal path forward to execute on this ethical mandate.

E. Education

Expanding reach and impact through educational initiatives is a natural fit for IPTA. These projects build on existing work supported by strongly engaged Education and Allied Health Committees and are designed to spread knowledge widely across multiple formats to IPTA members and beyond.

Action steps are:

1. **Engage** IPTA committee chairs as webinar hosts
2. **Develop** standardized formats, including video, print, audio, and social media
3. **Schedule** educational events; **Advertise** and promote widely
4. **Build** an IPTA library of material for member access, including Congress presentations.