



Annual Meeting at the  
American Academy of Ophthalmology 2021

# New Faces




**Anthony Broad**  
Clinical Program Manager



**Ivette Valle**  
Marketing & Communication Specialist

# UPCOMING CGRN: Kolokotronis > 2021



Childhood Glaucoma  
Research Network Presents:


An Educational Symposium  
for Eye Clinicians & Surgeons

**THE KOLOKOTRONIS LECTURE:**

**PATIENTS, PARENTS & PROVIDERS**  
Understanding and Measuring the Impact of Vision  
Impairment on Children and Young People.

**SATURDAY, JANUARY 29, 2022**  
10:00AM-11:00AM EDT  
Webinar Link: <https://miami.zoom.us/j93432463419>

**SPEAKER**



**Jugnoo Rahi,**  
**MB, BS, PhD, FRCOphtho**  
Great Ormond Street Hospital  
Professor of Ophthalmic Epidemiology & Hon.  
Consultant, NIHR Senior Investigator  
Head of: Vision & Eyes Group, Population Policy,  
Practice Research & Teaching Depts

## The Kolokotronis Lecture Series

### Patients, Parents & Providers, Part II

Understanding and Measuring the  
Impact of Vision Impairment on  
Children and Young People.

**Saturday, January 29, 2021**  
**10:00am EDT**



UKPGS: > 2021



- Professor **Anil Mandal**, Hyderabad, India
- Professor **Franz Grehn**, Mainz, Germany
- Professor **Alana Grajewski**, Miami, USA

## Join us at UK Paediatric Society 2022 Virtual meeting - Saturday 5 February 2022


**3 Pearls of Wisdom** Invited Speaker  
Lectures from past Noel Rice Lecturers

- **3** Abstract Presentation Sessions •
- **3** Panel Discussions •
- **3** Trainee Awards •
- Interactive Q&A •
- e-Meet & Chat •

Register @  
[www.ukpgs.org.uk](http://www.ukpgs.org.uk)



# CGRN Journal Club



**Hosted by**  
CGRN  
Samuel & Ethel Balkan International Pediatric Glaucoma Center  
Bascom Palmer Eye Institute

## VIRTUAL PEDIATRIC GLAUCOMA JOURNAL CLUB


Friday, September 17, 2021  
7:30 AM EDT

**Article: Quality of Life and Functional Vision in Children with Glaucoma**  
Annegret Dahlmann-Noor, MD, PhD, Vijay Tailor, MSc, Catey Bunce, DSc, Yassir Abou-Rayyah, MD, PhD, Gillian Adams, MD, FRCS, John Brookes, MD, FRCOphth, Peng T. Khaw, MD, PhD, Maria Papadopoulos, MD, FRCOphth

<http://dx.doi.org/10.1016/j.ophtha.2017.02.024> ISSN 0161-6420/17

**Presented by Sara Coulon, MD**  
Glaucoma Fellow, Bascom Palmer Eye Institute

**Link: <https://miami.zoom.us/j/93603006358>**  
Zoom Meeting ID: 93603006358



- Hosted by the CGRN and Bascom Palmer Eye Institute and The Samuel and Ethel Balkan International Pediatric Glaucoma Center
- Held quarterly

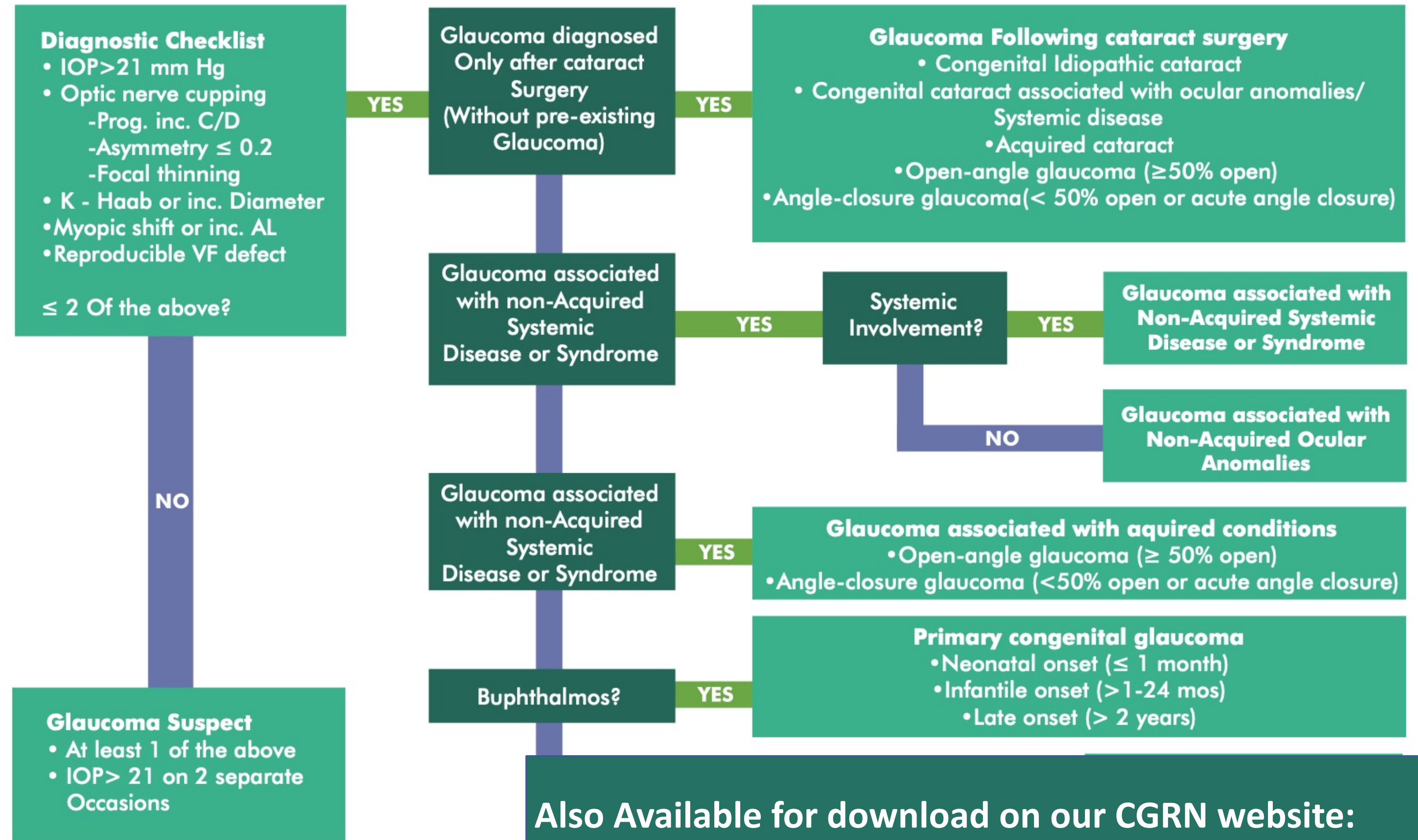
# Updates





# Classification of Childhood Glaucoma

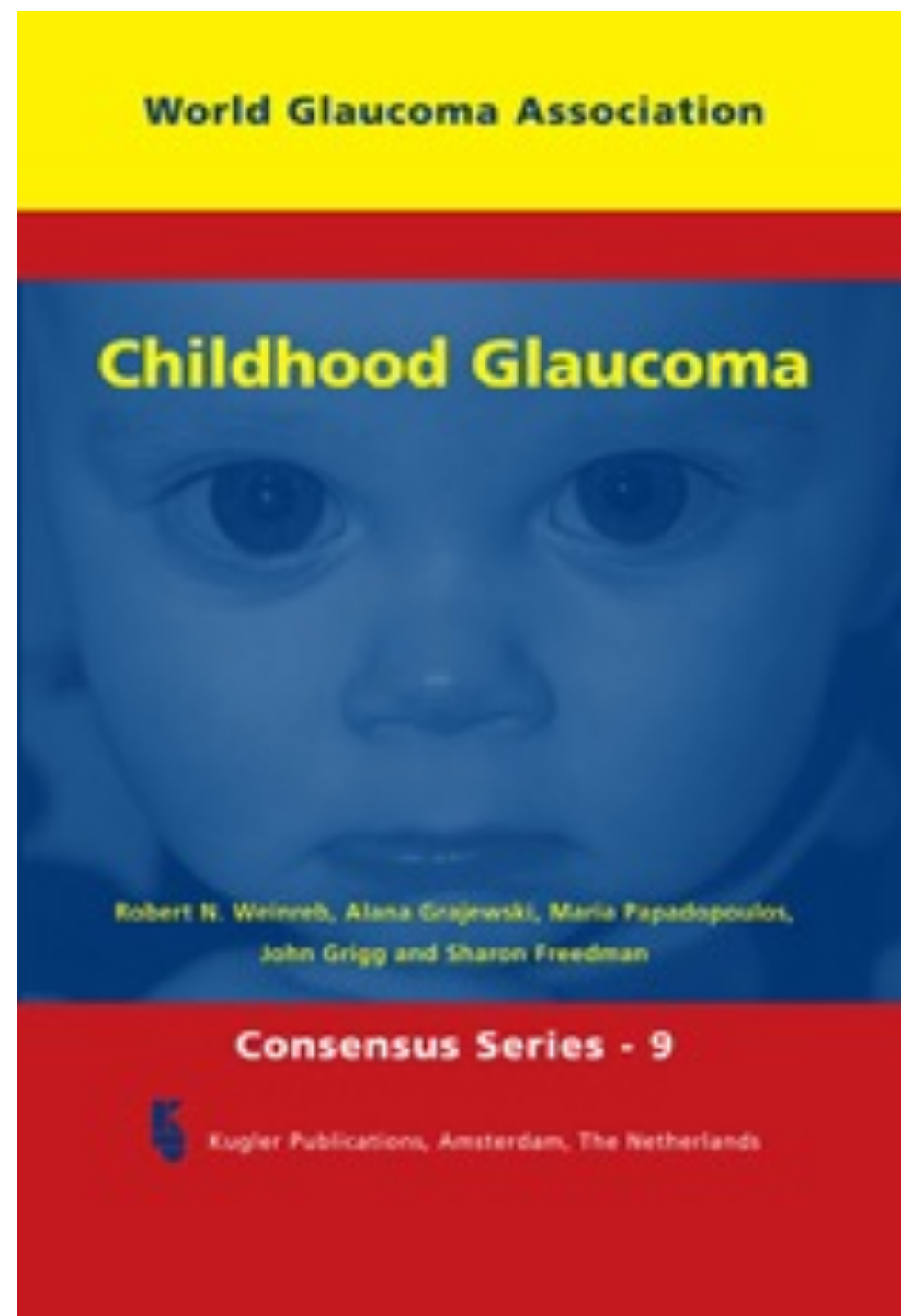
## Childhood Glaucoma Research Network



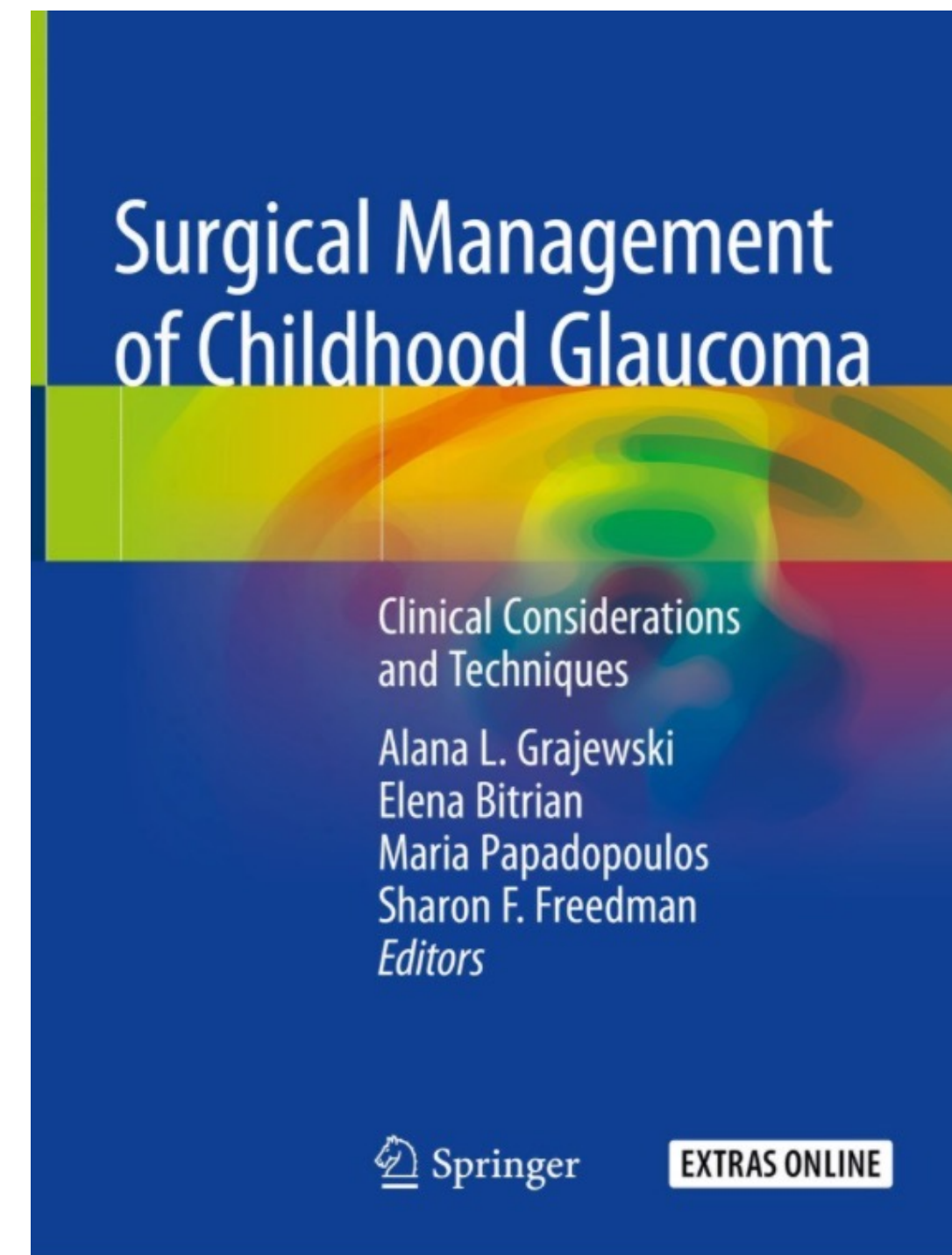
Also Available for download on our CGRN website:  
[www.childhoodglaucoma.com/](http://www.childhoodglaucoma.com/)



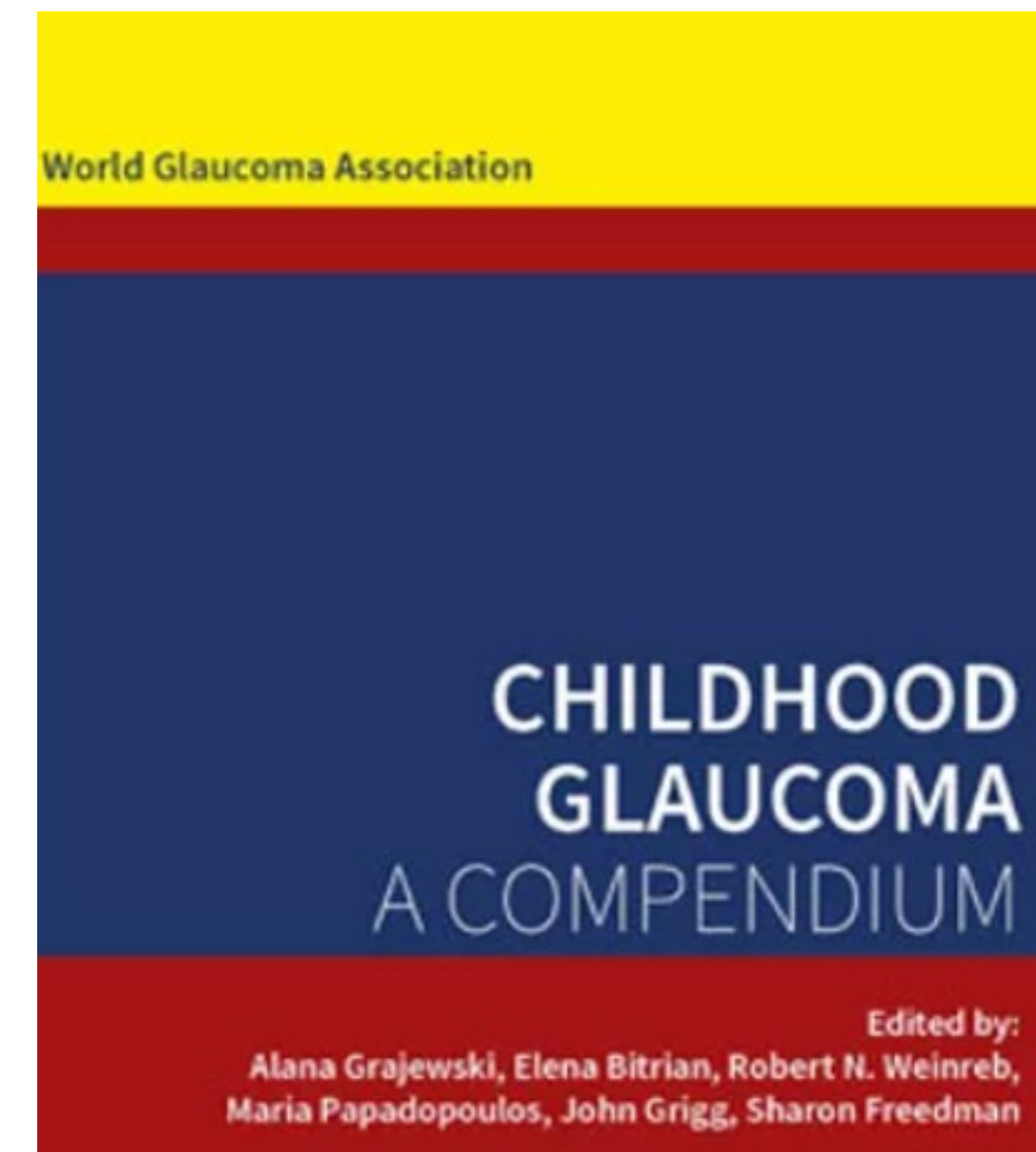
# TEXTBOOKS



Editors: R Weinreb A  
Grajewski, E Bitrian, M  
Papadopoulos, & S  
Freedman,



Editors: A Grajewski, E  
Bitrian, M  
Papadopoulos, & S  
Freedman



Editors: A  
Grajewski, E Bitrian,  
M Papadopoulos, &  
S Freedman





# Severity Staging System of Childhood Glaucoma

A Proposal for Multicenter CGRN Collaboration

**Huda Sheheitli**

Assistant Professor of Glaucoma  
University of Minnesota



# SSSCG: BACKGROUND



Establishing a staging system would allow clinician to use a standard severity scale for patient stratification in research studies and clinical trials worldwide.



This would help analyze the outcomes and efficacy of alternative treatments among the different disease severity states and ultimately guide treatment decision-making.



# METHODS

Childhood Glaucoma Research Network (CGRN), a consortium of childhood glaucoma tertiary care centers

- UC Davis, Dr. James Brandt as PI
- Akron Children Hospital, Dr. Rachida Bouhenni as PI
- Minnesota Lion's Children's Eye Clinic, Dr. Raymond Areaux as PI
- The Children's Mercy Hospital, Dr. Erin Stahl as PI
- Oregon Health & Science University (OHSU), Dr. Beth Edmunds as PI
- Centro Hospitalar Lisboa Norte (CHLN), Portugal, Dr. Luis Pinto as PI
- American University of Beirut, Lebanon, Dr. Christiane Al-Haddad as PI

Patients with childhood glaucoma (diagnosed prior to age of 18 years)

- Followed for at least five years

# HARLEY-CGRN INTERNATIONAL PEDIATRIC GLAUCOMA REGISTRY



Alex V. Levin,  
New Registry Coordinator, Randall Porter, MD  
Golisano Children's Hospital  
601 Elmwood Avenue, Box 659  
Rochester, NY 14642



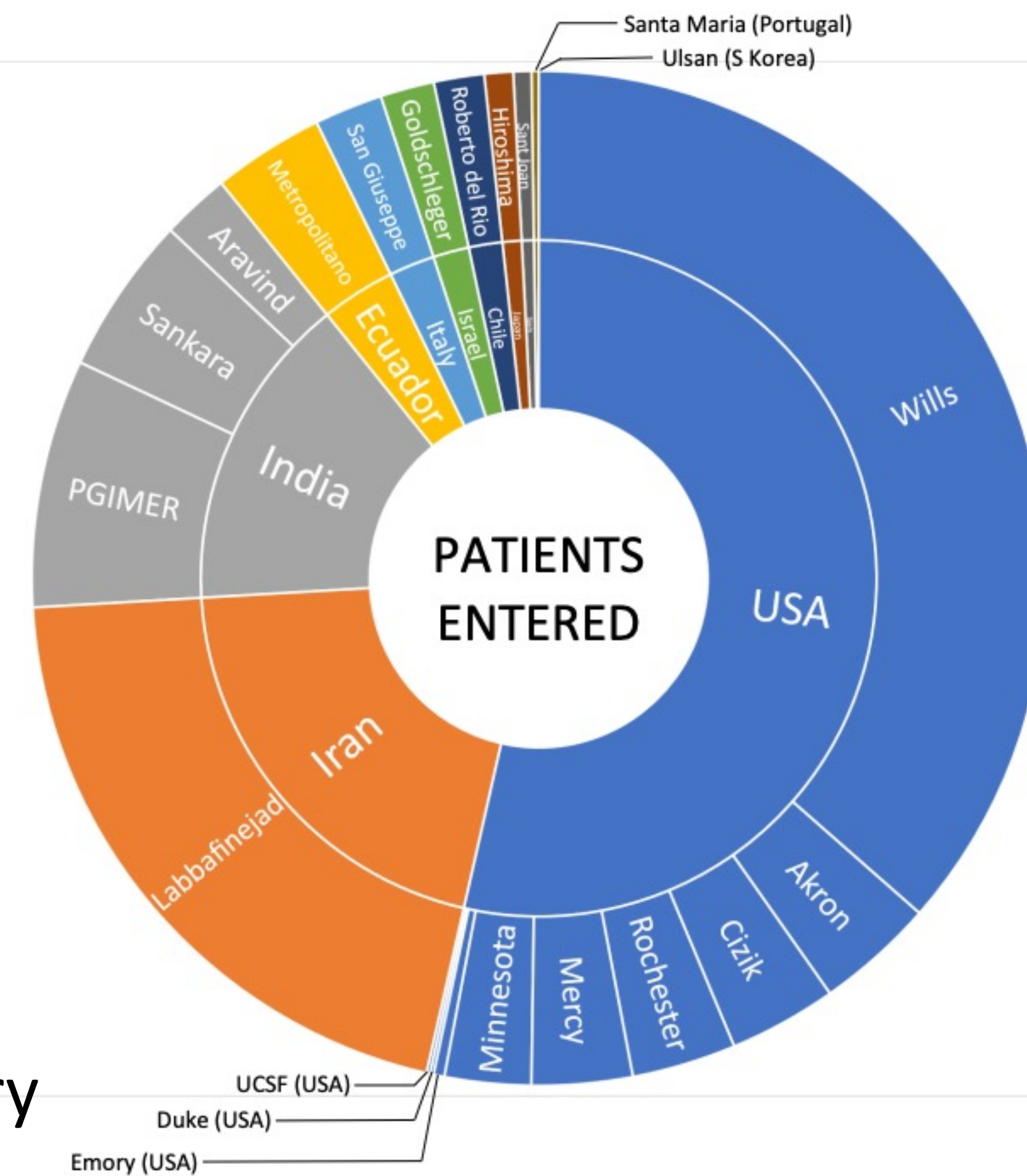
# DATA STATUS

- Approved Centers
- Centers Obtaining Approval
- Centers Indicating Interest



## Status of Registry:

- 900 patients with complete data entry
- 21 Centers



# MOVING INTO NEW CGRN PROJECTS





# New Movement



# 3PSI

Patients, Parents, and Providers Support Initiative





# Outline

3PSI Overview

Why We Care

What We Know

3PSI Goals

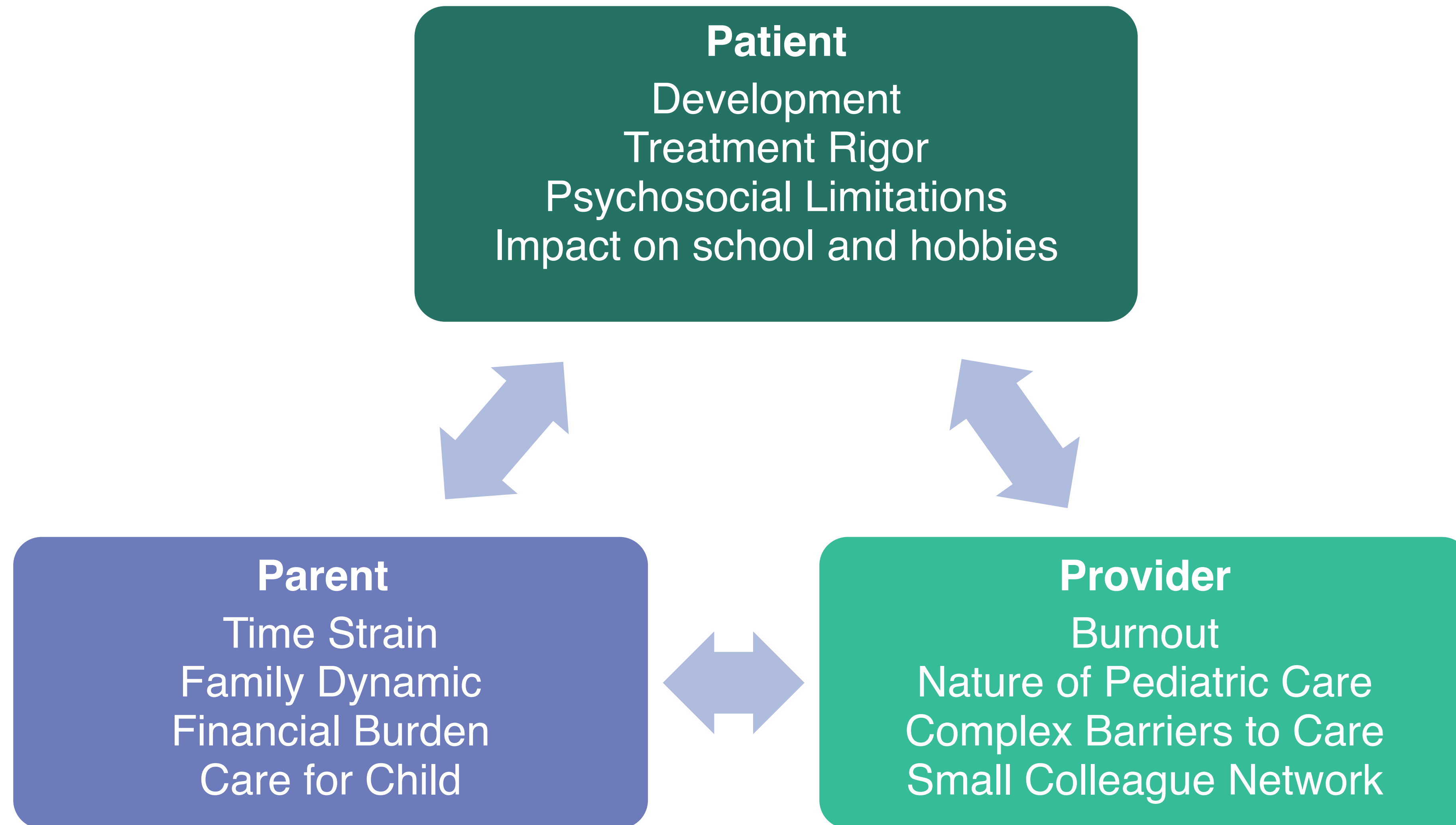
Current Projects

Future Steps

Discussion

# 3PSI:

## Patients, Parents, and Providers Support Initiative

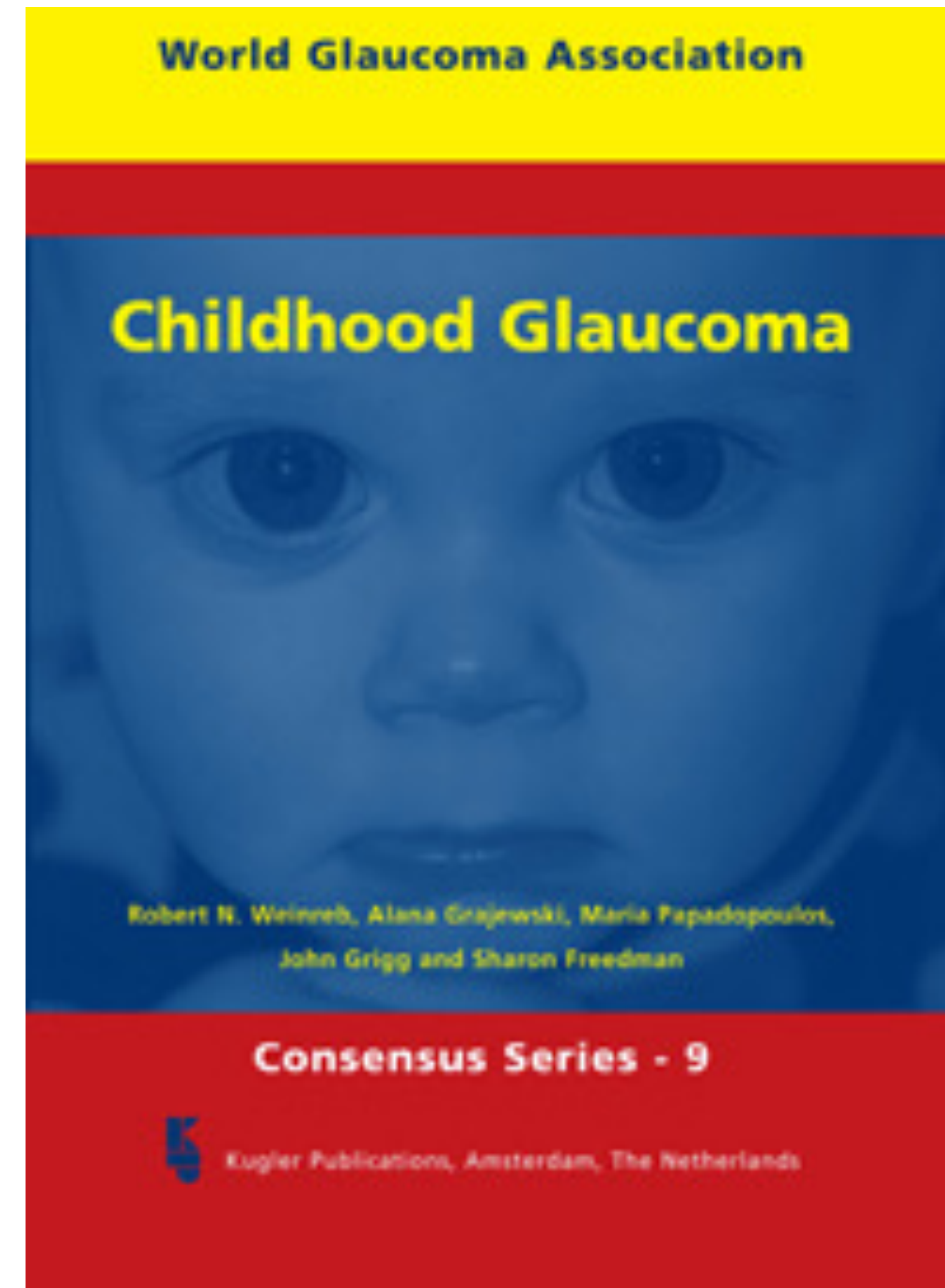


# Patients, Parents and Providers as Partners in Managing Childhood Glaucoma

Tanuja Dada, Jugnoo Rahi, Shveta Jindal Bali,  
Sharon Freedman

Childhood Glaucoma, pp. 249-254

Edited by Robert N. Weinrob, Alana L. Grajewski, Maria Papadopoulos, John Grigg,  
and Sharon Freedman 2013 © Kugler Publications, Amsterdam, The Netherlands





# Why We Care

Patient-reported outcome measures (PROMs)

Ophthalmic care, treatment compliance, and overall health outcome

Medical utilization and health care costs

Everhart RS, Greenlee JL, Winter MA, Fiese BH. Primary and Secondary Caregiver Reports of Quality of Life in Pediatric Asthma: Are They Comparable?. *Appl Res Qual Life*. 2018;13(2):371-383.

Freedman RB, Jones SK, Lin A, Robin AL, Muir KW. Influence of Parental Health Literacy and Dosing Responsibility on Pediatric Glaucoma Medication Adherence. *Arch Ophthalmol*. 2012;130(3):306–311. doi:10.1001/archophthalmol.2011.1788

Kantipuly A, Pillai MR, Shroff S, et al. Caregiver Burden in Primary Congenital Glaucoma. *Am J Ophthalmol*. 2019;205:106-114.

Neff JM, Anderson G. Protecting Children With Chronic Illness in a Competitive Marketplace. *JAMA*. 1995;274(23):1866–1869. doi:10.1001/jama.1995.03530230052030

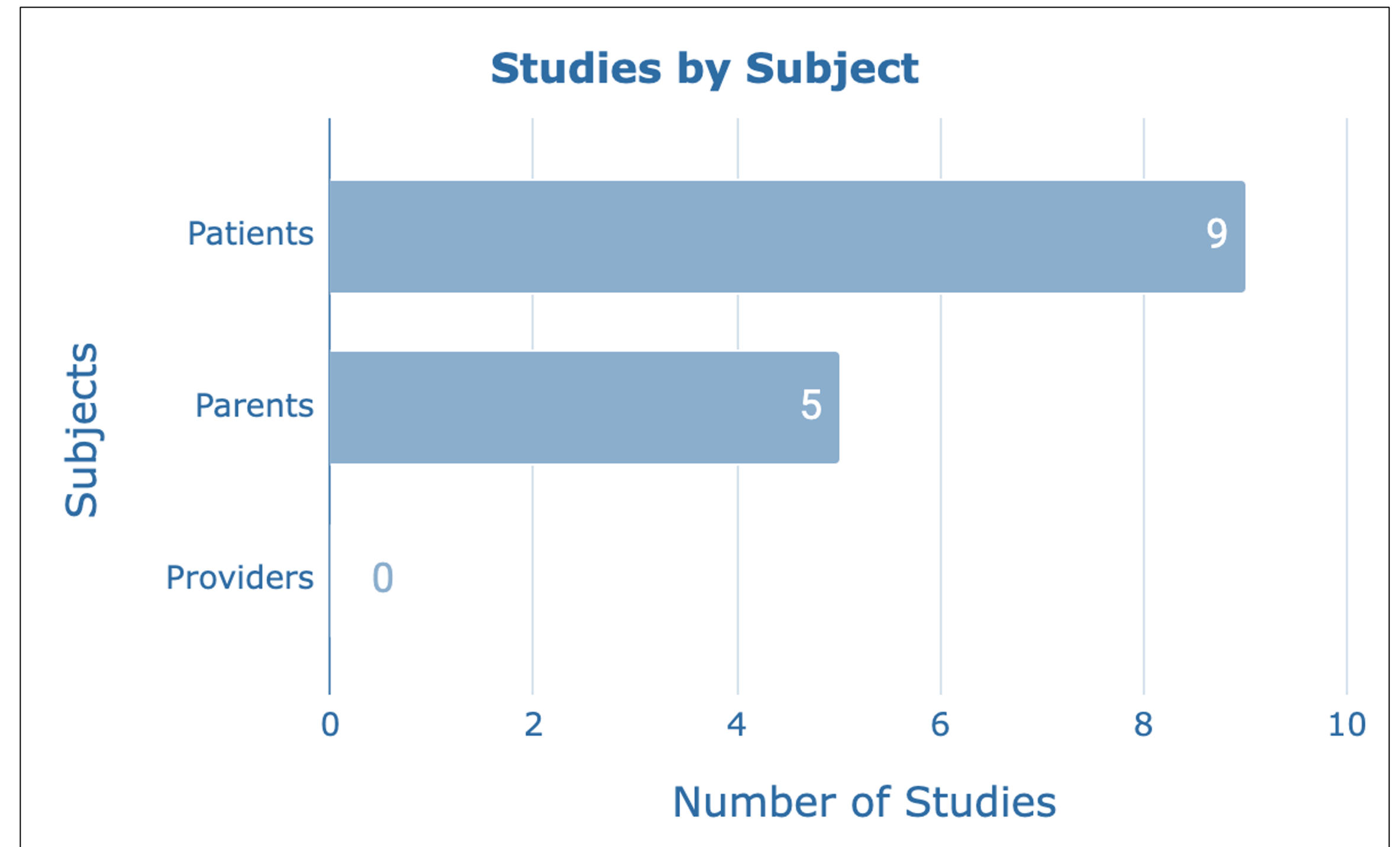
Tadic V, Hogan A, Sobti N, Knowles RL, Rahi JS. Patient-reported outcome measures (PROMs) in paediatric ophthalmology: a systematic review. *Br J Ophthalmol*. 2013;97(11):1369-1381. doi:10.1136/bjophthalmol-2013-303350

# What We Know

## Research is limited

## Pediatric glaucoma has considerable impact on patients and parents

- Children ranked psychosocial scores lower than physical scores.
- One-third of pediatric glaucoma caregivers reported moderate to severe depression.



Dada T, Aggarwal A, Bali SJ, Wadhwani M, Tinwala S, Sagar R. Caregiver Burden Assessment in Primary Congenital Glaucoma. *European Journal of Ophthalmology*. 2013;23(3):324-328.

Dahlmann-Noor A, Tailor V, Bunce C, et al. Quality of Life and Functional Vision in Children with Glaucoma. *Ophthalmology*. 2017;124(7):1048-1055.

Poongothai S, Pradeepa R, Ganesan A, Mohan V. Prevalence of depression in a large urban South Indian population--the Chennai Urban Rural Epidemiology Study (CURES-70). *PLoS One*. 2009;4(9):e7185. Published 2009 Sep 28. doi:10.1371/journal.pone.0007185

## 3PSI Goals

To normalize mental health assessment and intervention as part of the standard for Pediatric Glaucoma and Pediatric Anterior Segment care

To create a partnership between patient, parent, and provider to not only control the patient's disease, but to reduce the physical, psychological, social, and economic consequences of the disease



# Current Projects

## Kolokotronis Lecture: Patients, Parents, & Providers



**Jugnoo Rahi,  
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Great Ormond Street Hospital  
Professor of Ophthalmic Epidemiology & Hon.  
Consultant, NIHR Senior Investigator  
Head of: Vision & Eyes Group, Population Policy,  
Practice Research & Teaching Depts



**Alan Delamater, PhD, ABPP**

University of Miami Miller School of Medicine  
Professor of Pediatrics and Psychology  
Director, Clinical Psychology Dept. of Pediatrics

Part II (Upcoming): “Understanding and Measuring the Impact of Vision Impairment on Children and Young People” – January 29, 2022

## Extensive Literature Review on Impact of Visual Impairment on Children and Family Members

- Review Paper – In Progress

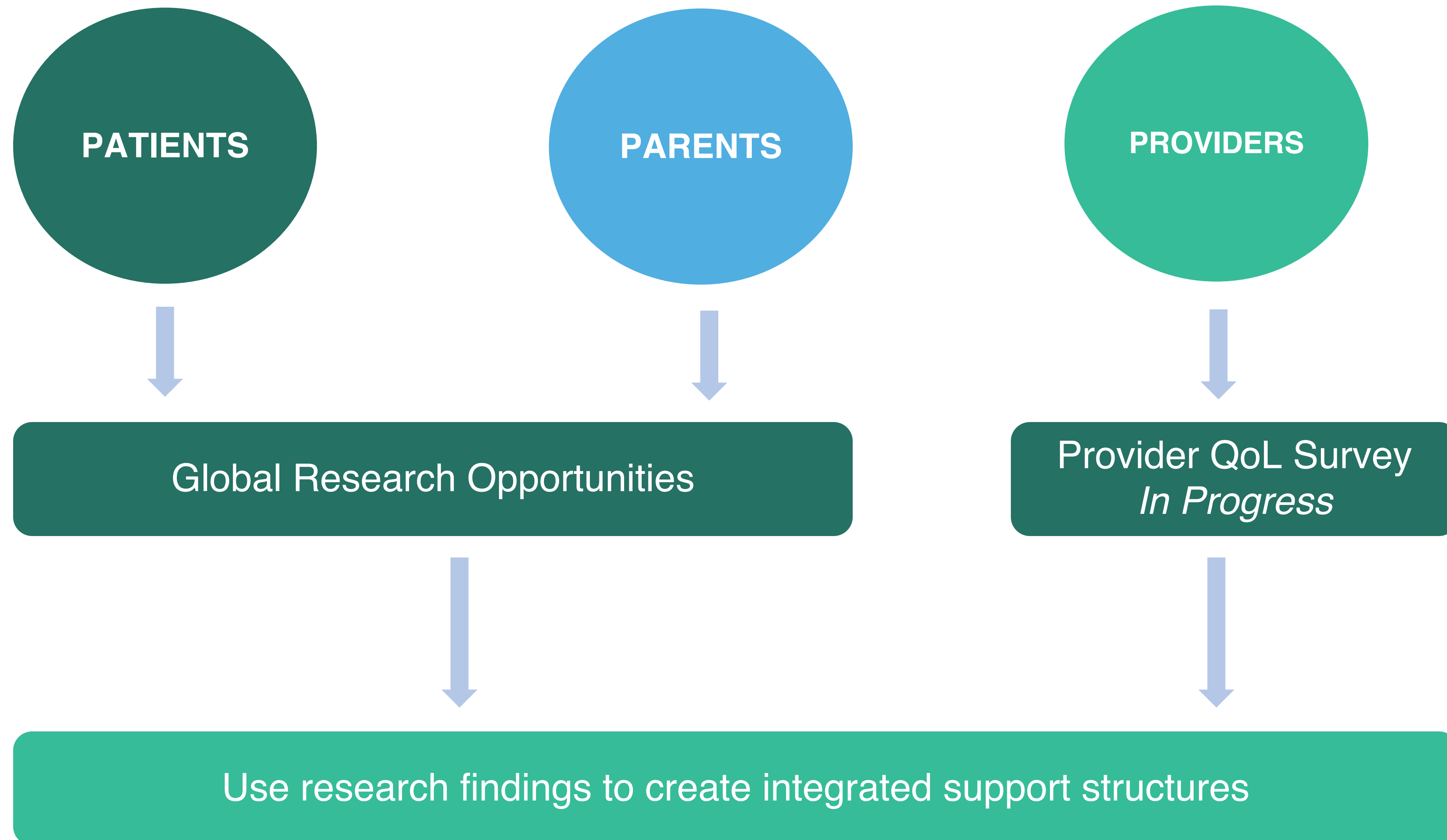
## Provider QoL Survey

- Open for responses



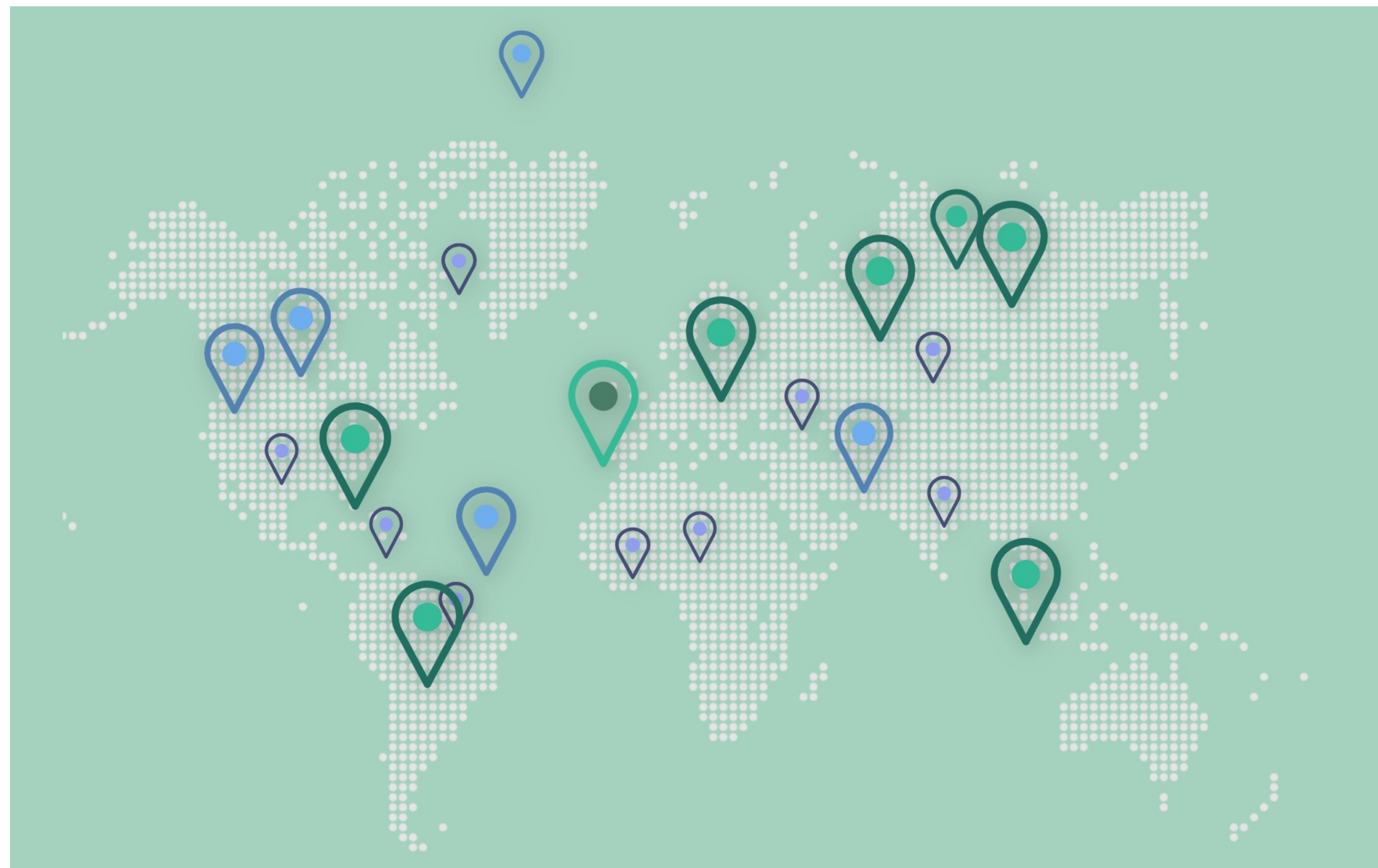
Provider QoL Survey

# Future Steps for CGRN





**We want to  
hear from you**



[www.childhoodglaucoma.com](http://www.childhoodglaucoma.com)




# KOLOKOTRONES INVITATION

## The Kolokotrones Lecture Series

Patients, Parents & Providers, Part II:  
Understanding and Measuring the  
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**Saturday, January 29, 2022 10:00am EDT**



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Practice Research & Teaching Depts

## Treating children with glaucoma is stressful, **how are you?**

Take this survey measuring

- Burnout
- Secondary Traumatic Stress
- Compassion Satisfaction



Scan for Provider QoL Survey

# References

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Dada T, Aggarwal A, Bali SJ, Wadhwani M, Tinwala S, Sagar R. Caregiver Burden Assessment in Primary Congenital Glaucoma. *European Journal of Ophthalmology*. 2013;23(3):324-328

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Janic A, Bowden S, Levy S, Stinson J, Dimaras H. Patient-reported outcome measures for retinoblastoma: a scoping review. *J Patient Rep Outcomes*. 2020;4(1):66. Published 2020 Aug 8. doi:10.1186/s41687-020-00232-7

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Kantipuly A, Pillai MR, Shroff S, et al. Caregiver Burden in Primary Congenital Glaucoma. *Am J Ophthalmol*. 2019;205:106-114.

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Tadić V, Cumberland PM, Lewando-Hundt G, Rahi JS; vision-related quality of life group. Do visually impaired children and their parents agree on the child's vision-related quality of life and functional vision?. *Br J Ophthalmol*. 2017;101(3):244-250. doi:10.1136/bjophthalmol-2016-308582

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Tadic V, Hogan A, Sobti N, Knowles RL, Rahi JS. Patient-reported outcome measures (PROMs) in paediatric ophthalmology: a systematic review. *Br J Ophthalmol*. 2013;97(11):1369-1381. doi:10.1136/bjophthalmol-2013-303350

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Weinreb, Robert N. *Childhood Glaucoma: The 9th Consensus Report of the World Glaucoma Association*. , 2013. Internet resource.





**THANK YOU**



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**UK Paediatric Glaucoma Society**

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## UK Paediatric Glaucoma Society Annual Meeting

**Saturday 5th February 2022**

Join us at the 2022 UKPGS meeting

Watch Live and On-demand - Ask a speaker a question -  
Delegate 1-2-1 Chat & Meet  
- 12-month access to our learning resource  
- 6 CPD points (RCOphth)



**Pearls of  
Wisdom  
Lecturers  
2022**



Leading international specialist paediatric  
glaucoma researchers and clinicians sharing  
research and clinical experience



We have decided to host the 2022 meeting virtually for second year.

We wish to ensure members of our paediatric glaucoma community can attend no  
matter where they reside around the world.

The format of the meeting will be very similar to that of [2021](#) (6 scientific sessions,  
32 abstract presenters, 3 Pearls of Wisdom Lectures).  
Visit the [2022 programme](#) for more information about the 2022 event.

**52 17 55**  
Days Hours Mins

[REGISTER](#)

CGRN  
Est. ARVO 2011

Website: [childhoodglaucoma.com](http://childhoodglaucoma.com)

YouTube Channel: [Childhood Glaucoma Research Network](#)

### Become A Member

Please Contact:

**Anthony Broad**

Clinical Program Manager

[balkancenter@miami.edu](mailto:balkancenter@miami.edu)

For technical support, to post materials of interest to CGRN members,  
or for feedback and suggestions.

