Childhood Glaucoma Research Network UKPGS • January 25, 2019





International association of physicians & scientists with an interest in childhood glaucoma

Membership is free and open to physicians and scientists with an interest in pediatric glaucoma

Our mission is to collaborate for clinical

treatment & research and to promote care for pediatric glaucoma

Guiding Principles: Support, Trust, Leadership, Transparency, Confidentiality, & Communication





200+ members

in 48 countries



Headquartered at The Samuel & Ethel Balkan

leadquartered at The Samuel & Ethel Balkar International Pediatric Glaucoma Center at Bascom Palmer Eye Institute

CGRN • Leadership





Allen D. Beck, MD

Emory Eye Center *Atlanta, GA*



Alana L. Grajewski, MD Bascom Palmer Eye Institute

Miami, FL



James D. Brandt, MD

UC Davis Health System Sacramento, CA

Freedman, MD

Sharon F.

Duke Eye Center

Durham, NC





Peng T. Khaw, PhD, FRCS Moorfields Eye Hospital *London, United Kingdom*

Maria Papadopoulos, MB, BS, FRACO Moorfields Eye Hospital London, United Kingdom



Robison D. Harley, MD CGRN International Pediatric Glaucoma Registry





Registry • About the Registry



De-identified database	Populated by users across the world	Secure and confidential
No cost to users	Participating users may use data for own research	Leverages large amounts of data on a rare disease for research purposes

Board Members:

Alex V. Levin, MD, MHSc
Sharon F. Freedman, MD
George L. Spaeth, MD
Allen D. Beck, MD
Vanessa Rangel Miller
Alana L. Grajewski, MD
David Mackey, MD



Please update the patient details. After you submit this form, you will then answer a survey about this person. Please page through the entire survey to the end to record your answers. You may add additional patients at the conclusion of the survey.

If you do not know the answers to any of the questions, you may return at any time and update or complete the profile or to add additional patients

Center Number:	01
Patient Number:	3713
Last Name of Person Entering Data:	Yassin
Birth Year:	T
Age:	T
Gender:	
Current Country:	▼▼
Country of Origin:	· · · · · · · · · · · · · · · · · · ·
Country of Origin:	• • •
Country of Origin:	T
Country of Origin:	T
Country of Origin.	
Glaucoma Diagnosis:	T
Age of Onset:	Ŧ
Age of Diagnosis:	Ŧ
Family History of same Glaucoma:	O Yes
	© No
	Unknown
Parent Consaguinity:	0 Yes
	© No
	Unknown but suspected constricted gene pool
	O Unknown
Referred by (Select all that apply):	Pediatric Ophthalmologist
	General Ophthalmologist
	Pediatrician/Family Physician
	Glaucoma Specialist
	Optometrist
	Non-Physician
	Not referred
Other referral (specify):	
Calent ather antices where the antices have been	
Select other centers where the patient has been previously seen	τ

Demographics

CGRN Classification Diagnosis IOP ≥21 mmHg Optic nerve cupping **Glaucoma Following Cataract Surgery** Increasing c/d Asymmetry ≤0.2 Focal thinning YES Glaucama dx'd <u>ONLY</u> after *Congenital cataract associated with ocular anomalies/systemic disease YES cataract surgery (without pre-existing Acquired cotoract K – Haab or inc. diameter Myopic shift or inc AL glaucama)? Myopic shit VF defect ♦Open angle glaucoma (≥50% open) Angle closure glaucoma (< 50% open or acute angle closur ≥2 of the above? Congenital eve NO Glaucoma Associated with Non-acquired Systemic anomalies or systemic Disease or Syndrome syndromes Glaucoma Associated with Non-acquired Ocular History of trauma, uveitis, YES Glaucoma Associated with Acquired Conditions •Open angle glaucoma (≥50% open) •Angle closure glaucoma (< 50% open or ocute angle trauma, steroid use tumor, ROP, etc? Primary Congenital Glaucoma Neonatal anset (<1 month) Infantile anset (>1-24 months) Buphthlamici ·Late onset (> 2 years) Juvenile Open Angle Glaucoma Glaucoma Suspect At least 1 sign per list (Confirm IOP > 21 on 2 separate Enter glaucoma diagnosis based on the CGRN classification system outlined above: Glaucoma Following Cataract Surgery. Open angle glaucoma (>50% open) Glaucoma Following Cataract Surgery. Angle closure glaucoma (<50% open or acute angle closure)</p> O Glaucoma Associated with Non-acquired Systemic Disease or Syndrome Glaucoma Associated with Non-acquired Ocular Anomalies Glaucoma Associated with Acquired Conditions. Open angle glaucoma (>50% open) O Glaucoma Associated with Acquired Conditions. Angle closure glaucoma (<50% open or acute angle closure) Primary Concenital Glaucoma, Neonatal onset (<1 month)</p> O Primary Congenital Glaucoma. Infantile onset (1-24 months) Primary Congenital Glaucoma. Late onset (>2 years) Juvenile Open Angle Glaucoma Next

Progress 0%

CGRN Classification Diagnosis

Progress 5% Diagnosis Date of Diagnosis Month v Select month and year of diagnosis . 1. IOP AT DIAGNOSIS Value Right Eye ۲ Left Eye Method Used Goldman Perkins Tonopen Icare Do not know Not applicable Other method (specify) 2. Examination Under Anesthesia (performed at diagnosis) No (continue to 3) Yes O Do not know (continue to 3) Anesthetic Used (Select all that apply) Not applicable Do not know Chloral Hydrate Fentanyl Isoflurane Ketamine Propofol Sevoflurane Other anesthesia used (specify) 3. OPTIC NERVE AT DIAGNOSIS Vicibilit Cup-to-Disk Ratio Localized Rim Notch Location of Notch (by clock hours) Right Ew

Diagnosis

T

•

•

Left

Eve

Progress		60%		
Filtering Procedures				
Date of Filtering Procedures with sclera	al flap (Trabeculectomy) - I	First procedure		
Right Eye [Left Eye [Month		Year	
Filtering Procedures with scleral flap (T	rabeculectomy) - First pro	ocedure		
Flap Right Eye Left Eye	Qua	adrant T	Antifibrotic agent Used	Antifibrotic agent
Date of Filtering Procedures with sclera	al flap (Trabeculectomy) - 3	Second Procedure		
Right Eye [Left Eye [Month		Year	
Filtering Procedures with scleral flap (T	rabeculectomy) - Second	Procedure		
Flap Right Eye Left Eye	Qua	adrant V	Antifibrotic Agent Used	Antifibrotic Agent
Date of Filtering Procedures with sclera	al flap (Trabeculectomy) -	Third Procedure		
Right Eye [Left Eye [Vonth Vonth		Year	
Filtering Procedures with scleral flap (T	rabeculectomy) - Third pro	ocedure		
Flap Right Eye	▼	adrant T	Antifibrotic Agent Used	Antifibrotic Agent
Filtering Procedures without scleral flap				
Trephination Thermal Sclerostomy Iridencleisis Posterior lip Sclerectomy	Number of times performed	Month of surgery		urgery ▼ ▼ ▼
Filtering Procedures without scleral flap	o - Left Eye			
Trephination Thermal Sclerostomy	Number of times performed	Month of surgery		urgery T

Medical Treatment							
Medications - Right Eye							
	First Visit	3 months after 1st visit	6 months after 1st visit	12 months after 1st visit	2 years after 1st visit	3 years after 1st visit	4 years after 1st visit
Timolol							
Levobunolol							
Metipranolol							
Carteolol							
Betaxolol							
Dipivefrin							
Apraclonidine							
Brimonidine							
Acetazolamide							
Methazolamide							
Dorzolamide							
Brinzolamide							
Latanoprost							
Unoprostone							
Travoprost							
Bimatoprost							
Miochol E							
Pilocarpine							
Atropine							
Phenylephrine							
Cyclopentolate							
Tropicamde							
Other							
Steroids (topical)							
NSAIDs (topical)							
Medications - Left eye							

97%

99%

Post-Treatment Follow-up

Progress

Post-treatment Follow-up - Right Eye For corneal thickness, round measures ending with 5 or higher to the next 10. Corneal Thickness Visual Acuity IOP 3 months ۲ ۲ ۲ 6 months ¥ ¥ T 12 months T ¥ T ¥ ¥ 2 years ۲ 3 years ¥ T • 4 years ¥ ¥ T Post-treatment Follow-up - Left Eye For corneal thickness, round measures ending with 5 or higher to the next 10. Visual Acuity IOP Corneal Thickness 3 months ¥ ¥ ۲ • 6 months ۲ ۲ ۲ 12 months ¥ ۲ ¥ ¥ 2 years Ŧ ۲ 3 years Ŧ ¥ ۲ • 4 years ¥

Next

Registry • Get Involved



Contact Dr. Alex Levin alevin@willseye.org expressing interest

We send: protocol, informed consent/assent, Wills Eye Hospital IRB approval letter



Apply to your institution IRB

Send us your IRB approval letter



Username and password will be created Start entering patient information





Global Eye SITE®

Changing the way the world treats children with glaucoma



Global Eye SITE® • About

The Global Eye Site® curriculum includes the workup and management of childhood glaucoma, ocular syndromes, and ocular genetics. Participants are given the opportunity to work with leading specialists in pediatric glaucoma, pediatric ophthalmology, and genetics from the University of Miami at The Balkan Center

Global Eye SITE® promotes a culture of continuous learning, ultimately increasing the availability of physicians in an area dedicated to saving the sight and changing the lives of children with glaucoma. This allows Global Eye SITE® to have a lasting and growing impact on reducing preventable blindness due to glaucoma worldwide

Identify **Passionate** Anterior Segment Surgeon(s) from an Area of Need (USA *and* Worldwide)

2 Week to 3 Month Observership **at** Bascom Palmer Eye Institute in the Treatment & Management of Pediatric Glaucoma C Br

Return Home to Provide Care & Train Others to Increase Availability of Specialized Care





Tina Damarjian

Catherine Thuruthumaly

Dr. Damarjian was the first domestic observer to participate in Global Eye SITE[®]. At the time of her observership, she was the only physician in the state of Wisconsin treating patients with childhood glaucoma. Dr. Thuruthumaly then participated in a Global Eye SITE[®] observership and will be assisting The Balkan Center with the creation of a pediatric uveitis and glaucoma clinic in Miami. Global Eye SITE® observerships are open to surgeons from ALL areas of the globe, not only outside the United States.

Both Dr. Damarjian and Thuruthumaly practice in rural midwestern USA, where there is a need for physicians who treat pediatric glaucoma.



Lucas Nicacio São Paulo Brazil

Dr. Nicacio left his home and practice in rural Brazil to be the first observer to spend 3 months in Miami immersing himself in the training and education of pediatric glaucoma. He has since returned home, caring for Nicolly (who's treatment for her pediatric glaucoma made viral news) and pediatric glaucoma patients of his area.





Michael Siban

Suriname Eye Centre Suriname

Dr. Siban joined us from the Caribbean nation of Suriname to become the first pediatric glaucoma specialist in his country. He was joined by his wife during the 3 month stay in Miami .

Since his return home, he has been able to provide pediatric glaucoma care. Dr. Siban is now a key investigator in CGRN's Pediatric Preventable Blindness Initiative in Suriname.



Eldar Rosenfeld

Tel Aviv Israel

Dr. Rosenfeld joined us for 3 months from the Tel Aviv Sourasky Medical Center and the University of Tel Aviv.

Israel has ones of the highest rates of pediatric glaucoma.

Dr. Rosenfeld is formalizing a Center dedicated to Pediatric Glaucoma Center at his home institution, collaborating with others in his region.



Angelina Ampong & Doreen Amankwaa-Frempong KNUST School of Medical Sciences Ghana



In collaboration with Orbis, we recently hosted 2 physicians from Ghana to received specialized pediatric glaucoma training.

They then joined Dr. James Brandt at the UC Davis Medical Center.





Our Next Observer:

Sylvia Groth

Vanderbilt University Nashville, Tennessee



Pediatric Preventable Blindness

Our mission to reduce preventable blindness in children, worldwide



PPB Introduction



The primary objective of Pediatric Preventable Blindness (PPB) is to address preventable blindness by developing and implementing a sustainable framework of early vision screening in infants and children that can be applied globally.

This initiative is being conducted in conjunction with the University of the West Indies.

Phase 1: The Suriname Project will build on the country of Suriname's pre-existing childhood vaccination infrastructure to provide vision screenings to infants and children.

After Phase 1: Our goal is to implement this method of early vision screening throughout other areas of the Caribbean

PPB • Phase 1: Suriname

- The Republic of Suriname is a sovereign nation on the Atlantic Coast of South America, bordering French Guyana, Guyana, Brazil, and the Atlantic Ocean at a size of 63,252 square miles. Suriname was colonized by the Dutch from 1647 until independence in 1975.
- Suriname is considered to be a Caribbean nation
- Population: 568,300
 - 31% are children with approximately 10,000 births per year
 - 90% live on the northern coast or near the capital city Paramaribo - the remaining 10% live in the interior districts



CGR



In collaboration with ophthalmologists at the Suriname Eye Centre, The Suriname Project will build on the current well-established infrastructure that provides mandatory vaccinations for infants through community health workers in private and government-sponsored clinics.

Community health workers will be taught to use a handheld vision screening device.

No previous knowledge on vision screening or eye diseases is needed to do this. Patients will be referred the pediatric ophthalmologist for a comprehensive vision exam if any risk factors are identified.



Due to the high vaccination rates in Suriname, we believe providing vision screenings while children are in clinics receiving vaccines is the best method of execution.

By capitalizing on the current program, we aim to maximize the long term sustainability of The Suriname Project by limiting the need for more time, staff, and resources.



Vaccination Rate in Suriname: An Average from 2015 to 2017 ¹⁸					
Vaccine Type	Birth	2 Months	6 Months	12 Months	
Нер В	75.00%				
IPV 1		65.33%			
Pentavalent 1		90.67%			
OPV 3			82.67%		
Pentavalent 3			87.00%		
GK				81.33%	
MMR 1				96.00%	
Grand Total	75.00%	78.00%	85.92%	91.11%	

As shown above, across a 3 year average, 84.80% of children received their necessary vaccinations.

Children have 6 points of contact with community health workers for vaccinations from birth until 18 months, falling within the acceptable range for early vision screening. Description of Vaccinations Pentavalent: Diphtheria, Pertussis (Whooping Cough), Tetanus, Hepatitis B and Haemophilus Influenzae Type B (Hib) IPV: Inactivated Polio OPV: Oral Poliovirus MMR: Measles, Mumps, and Rubella GK: Yellow Fever



Severity Staging System of Childhood Glaucoma

SSSCG Introduction



Purpose: Conduct a "Severity Staging System of Childhood Glaucoma" through the retrospective review of the medical records of children with glaucoma, constructing a model to predict outcome

Importance: Disease severity scales are an important adjunct to disease classification and an important part of stratification for clinical trials. A severity scale allows prediction of patient outcome, comparison of quality-of-care, improvement in clinical decision-making and stratification for clinical trials.

Impact: Severity Scale will assist the physician caring for children with glaucoma in clinical decision-making. It sets the stage for stratification for future collaborative CGRN clinical trials.

SSSCG Health Outcome Measurements

The purpose of this study is to calibrate and validate a proposed "Severity **Staging System of Childhood Glaucoma**" (SSSCG) by conducting a retrospective review of medical records

Disease Severity Staging System Context
Clinical Trials
Intervention

Outcome

- Prognostication
- Resource Allocation



SSSCG • Get Invovled





http://bit.ly/SSSCG

Link is case sensitive Visit the link above for info

Contact:

Huda Sheheitli hxs691@med.miami.edu

Johnathan Pangborn jpangborn@miami.edu



SSSCG • Prospective Participants

Send contact information @ hxs691@med.miami.edu & http://bit.ly/SSSCG

Schedule a phone conference with Dr. Chang, Dr. Sheheitli, and Dr. Grajewski

Get Institutional Review Board Approval. We will assist with this!



Review records and upload data





World Glaucoma Association

Childhood Glaucoma

Robert N. Weinreb, Alana Grajewski, Maria Papadopoulos, John Grigg and Sharon Freedman

Consensus Series - 9

Kugler Publications, Amsterdam, The Netherlands

WGA CONSENSUS FOR PURCHASE KUGLERPUBLICATIONS.COM

Childhood Glaucoma

Edited by: R.N. Weinreb & A.L. Grajewski & M. Papadopoulos & J. Grigg & S. Freedman Also available in Spanish!

Childhood Glaucoma Compendium

Edited by: A.L. Grajewski, E. Bitrian, R.N. Weinreb, M. Papadopoulos, J. Grigg & S. Freedman



The purpose of this spiral bound publication is to collect in a visual and practical format useful content from the Consensus Series 9 book. Perfect for the clinic and a great quick reference.

Surgical Management of Childhood Glaucoma

Clinical Considerations and Techniques

Alana L. Grajewski Elena Bitrian Maria Papadopoulos Sharon F. Freedman *Editors*

Description Springer

EXTRAS ONLINE

NOW AVAILABLE ON SPRINGER.COM

Editors: Alana Grajewski, Elena Bitrian, Maria Papadopoulos, Sharon Freedman

- Practical and illustrative guide for ophthalmologists
- Dozens of surgical videos and color illustrations and intraoperative pictures
- Surgical techniques from angle surgery to trabeculectomy, glaucoma drainage devices or cycloablation procedures
- Guides the reader step-by-step along the surgical procedures

Publications • CGRN Classification System



REVIEW



New classification system for pediatric glaucoma: implications for clinical care and a research registry

Avrey Thau^{a,b}, Maureen Lloyd^{a,b}, Sharon Freedman^c, Allen Beck^d Alana Grajewsk[®], and Alex V. Levin^{a,b}



Purpose of review

The Childhood Glaucoma Research Network (CGRN) has created a new classification system for childhood glaucoma that has become the first International Consensus Classification. The purpose of this review is to present this classification system and share its use to date.

Recent Findings

The diagnoses of the classification system include glaucoma and glaucoma suspect. The primary glaucomas include: primary congenital glaucoma and juvenile open-angle glaucoma. The secondary glaucomas include: glaucoma following cataract surgery, glaucoma associated with nonacquired systemic disease or syndrome, glaucoma associated with nonacquired ocular anomalies, and glaucoma associated with acquired conditions. This system reached consensus agreement at the Ninth World Glaucoma Association Consensus, which has been adopted by the American Board of Ophthalmology, and has been implemented in outcomes research, incidence studies, and review articles. The new Robison D. Harley, MD CGRN International Pediatric Glaucoma Registry uses this classification system as a shared language, allowing international clinicians and researchers to collaborate and make large-scale investigations of this otherwise rare disease possible.

Summary

The diagnoses in this system are assigned by following a logical and systematically approachable path. The ability to easily adopt and implement the system lends itself to international research.

Keywords

childhood glaucoma, international, international classification, pediatric glaucoma, research

Thank You!

