Fight RB, India

RB India National Stakeholder Group

12 Years

of Hope | Impact | Change

NATIONAL RETINOBLASTOMA CONCLAVE REPORT 2026

Near-Universal Access to
Retinoblastoma Care in India







The Patient Must Always Remain at the Centre





19
Institutions in 2014

90
Treatment Centres in 2026

1,676+
Children Diagnosed Annually

A First for Childhood Cancer Care in India

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COVER LETTER

Dear Colleagues, Partners and Friends,

We are pleased to share the report of the 14th Fight RB India Stakeholder Meeting and National Retinoblastoma Conclave 2026, held on 16 May 2026 at the Constitution Club of India, New Delhi.

The conclave brought together survivors, parents, ophthalmologists, pediatric oncologists, pediatricians, healthcare professionals, researchers, policymakers, civil society organizations, donor partners and national professional bodies to reflect on India's progress in Retinoblastoma care and to chart the course towards Vision 2030.

A defining feature of the conclave was its commitment to patient-centred care. The programme was moderated and anchored by Retinoblastoma survivor and parent ambassadors from across India, reflecting a core belief of the Fight RB India movement—that the patient must always remain at the centre of the system we seek to build.

The conclave also marked a historic milestone with the validation of near-universal access to specialised Retinoblastoma care in India. What began in 2014 as a collaborative initiative involving 19 institutions has evolved into a nationwide stakeholder movement comprising nearly 90 treatment centres, professional societies, healthcare institutions, researchers, survivors, parent advocates, civil society organizations and government partners working together towards a common purpose.

This achievement is believed to represent the first documented example of a childhood cancer in India achieving near-universal access through a coordinated stakeholder movement. It demonstrates what is possible when science, systems, advocacy and patient voice come together in pursuit of better outcomes for children.

The report that follows documents this remarkable journey, celebrates the achievements of the Fight RB India movement, captures key insights and recommendations emerging from the conclave, and presents a shared vision for the future of Retinoblastoma care in India.

We sincerely acknowledge the contributions of all stakeholders, survivors, parent advocates, healthcare professionals, researchers, professional societies, healthcare institutions, donor partners and government representatives who have contributed to the growth and success of the Fight RB India movement over the past decade.

CanKids...KidsCan
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As we look towards Vision 2030, we remain committed to ensuring that every child with Retinoblastoma has access not only to timely diagnosis and quality treatment, but also to vision preservation, rehabilitation, survivorship support and the opportunity to thrive.

We hope this report will strengthen collaboration, inspire continued action and accelerate progress towards better outcomes and quality of life for every child and family affected by Retinoblastoma.

Save Life • Save Eye • Save Vision

On behalf of the Fight RB India Architects and Secretariat

Poonam Bagai
Cancer Survivor, Patient Advocate & Philanthropist
Founder Chairman, CanKids KidsCan
Architect, Fight RB India

Dr. Santosh Honavar
International Ocular Oncologist
Architect, Fight RB India

Dr. Amita Mahajan
Senior Pediatric Oncologist
Lead, Suddridh OCAT, CanKids KidsCan
Architect, Fight RB India

Dr. Haresh Gupta
Senior Development Professional
Deputy CEO & Chief of Programs, CanKids KidsCan
Secretariat, Fight RB India

Dr. Seema Das
Senior Ocular Oncologist
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Dr. Neelima Thakur
Senior Development Professional
Head – Medical Affairs, CanKids KidsCan
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ABBREVIATIONS

RB	Retinoblastoma
NITI	National Institution for Transforming India
NHA	National Health Authority
AIOS	All India Ophthalmological Society
IAP	Indian Academy of Pediatrics
InPHOG	Indian Pediatric Hematology Oncology Group
PHO Chapter	Pediatric Hematology Oncology Chapter
YANA	You Are Not Alone
IAC	Intra-Arterial Chemotherapy
IVC	Intravitreal Chemotherapy

EXECUTIVE SUMMARY

National Retinoblastoma Conclave 2026

The National Retinoblastoma Conclave 2026 brought together survivors, parents, clinicians, researchers, healthcare institutions, policymakers, professional societies and advocacy organizations to celebrate India's progress in Retinoblastoma care and chart the course toward Vision 2030.



A major milestone celebrated during the conclave was the validation of near-universal access to Retinoblastoma care in India. This achievement is believed to represent the first documented example of a childhood cancer in India achieving near-universal access through a coordinated stakeholder movement.

From a network of 19 institutions and one Civil Society Organization in 2014, Fight RB India has expanded into a nationwide movement comprising 90 treatment centres, several CSOs, more than 130 specialists, development sector professionals, parents, survivors, patient advocacy groups and RB Ambassadors committed to improving outcomes for children with Retinoblastoma.

India estimates approximately 1,676 new Retinoblastoma cases annually. Through sustained efforts in awareness generation, referral strengthening, supportive care, financial assistance, research collaboration and stakeholder engagement, most children diagnosed with Retinoblastoma now have access to specialized treatment services.

The conclave highlighted progress across five major areas:
Access – Expansion of treatment centres, referral pathways and patient navigation support.
Quality – Standardized treatment approaches, multidisciplinary care and collaborative learning.
Research – Multicentric collaboration through the InPOG-RB-19-01 study involving more than 1,120 children across 20 centres.

Advocacy – Partnerships with AIOS, IAP, InPHOG, government agencies and survivor networks.
Survivorship – Growing emphasis on rehabilitation, psychosocial care, education, eye salvage, vision preservation and quality of life.

INDIA IS FIGHTING RB — AND WE ARE WINNING

The National Retinoblastoma Conclave 2026 brought together survivors, parents, clinicians, researchers, policymakers, healthcare institutions, professional societies, civil society organizations and donor partners to celebrate progress and define the future of Retinoblastoma care in India.

A defining feature of the conclave was its survivor-led and family-centred approach. The programme was moderated and anchored by Retinoblastoma survivor and parent ambassadors representing different parts of India, reinforcing the principle that meaningful patient-centred care must place the patient voice at the centre.



The conclave opened with a moving Saraswati Vandana by survivor Janki Gupta, symbolizing resilience, hope and possibility.

Throughout the day, survivors and parents shared personal journeys that highlighted the realities of diagnosis, treatment, rehabilitation, education, employment and survivorship. Their stories served as a reminder that behind every statistic lies a child, a family and a future worth fighting for.

Participants reflected on the remarkable journey of Fight RB India and celebrated the validation of near-universal access to Retinoblastoma care across the country.

The conclave was further strengthened by messages of support and congratulations from Dr. M. Srinivas, Member, NITI Aayog, Govt of India, Dr. Jeevan Titiyal, President, All India Ophthalmological Society (AIOS), Dr. Neelam Mohan, President, Indian Academy of Pediatrics (IAP), and Dr. Ramandeep Arora, President, Indian Pediatric Hematology Oncology Group (InPHOG). Their messages acknowledged the remarkable progress achieved through the Fight RB India movement and reaffirmed the importance of continued collaboration to improve survival, vision preservation, financial protection and quality of life for children affected by Retinoblastoma.

“This is a landmark achievement not only for childhood cancer care, but for cancer care in India. It demonstrates what is possible when clinicians, institutions, civil society, survivors and policymakers work together towards a shared goal.”

— Dr. M. Srinivas, Member, NITI Aayog, Govt of India

The conclave also marked several important milestones including the launch of the Retinoblastoma Resource and Centres Directory, the release of a landmark publication in the Indian Journal of Ophthalmology documenting India’s Retinoblastoma journey, and the screening of the national appeal film:

“Mr Prime Minister – Do You See What EYE See?”

Together, these milestones reflected a growing national commitment to ensuring that every child with Retinoblastoma receives timely diagnosis, quality treatment, financial protection and survivorship support.

Stakeholders acknowledged that the next phase of work must focus on survival, financial protection, rehabilitation, eye salvage, vision preservation and long-term survivorship.

The conclave concluded with a shared Vision 2030 commitment centred on:

- 80–90% survival
- Early diagnosis and timely referral
- Equitable access to care
- Vision preservation
- Financial protection
- Standardized treatment systems
- Research and innovation
- Comprehensive survivorship support

The National Retinoblastoma Conclave 2026 reaffirmed a collective national commitment to ensuring that every child with Retinoblastoma in India receives timely diagnosis, quality treatment, survivorship support and the opportunity to live a healthy and dignified life.

India is Fighting Retinoblastoma.
And together, we are winning.



MESSAGES FROM
NATIONAL LEADERS AND PARTNERS



It gives me great pleasure to join you during International Retinoblastoma Week and to congratulate Fight Retinoblastoma India, CanKids India, clinicians, researchers, survivors, parents, patient advocacy groups, and all stakeholders on achieving an important national milestone — near-universal access to care for children with retinoblastoma.

This is a landmark achievement, not only among childhood cancers but among cancers in India as a whole. It demonstrates what is possible when government institutions, medical professionals, researchers, civil society organizations, patient groups, survivors, and philanthropic partners come together with a shared purpose and a patient-centric approach.

Retinoblastoma is a rare but highly curable childhood eye cancer. Early detection and timely treatment can save lives, preserve vision, and protect childhood itself. Over the last decade, Fight Retinoblastoma India has emerged as a shining example of stakeholder collaboration and patient-centric care through a collaborative network of 90 retinoblastoma treatment centers across India. By integrating pediatric oncology and ocular oncology expertise, access to diagnosis and treatment has significantly improved across the country, creating a true pan-India network of care for children and their families.

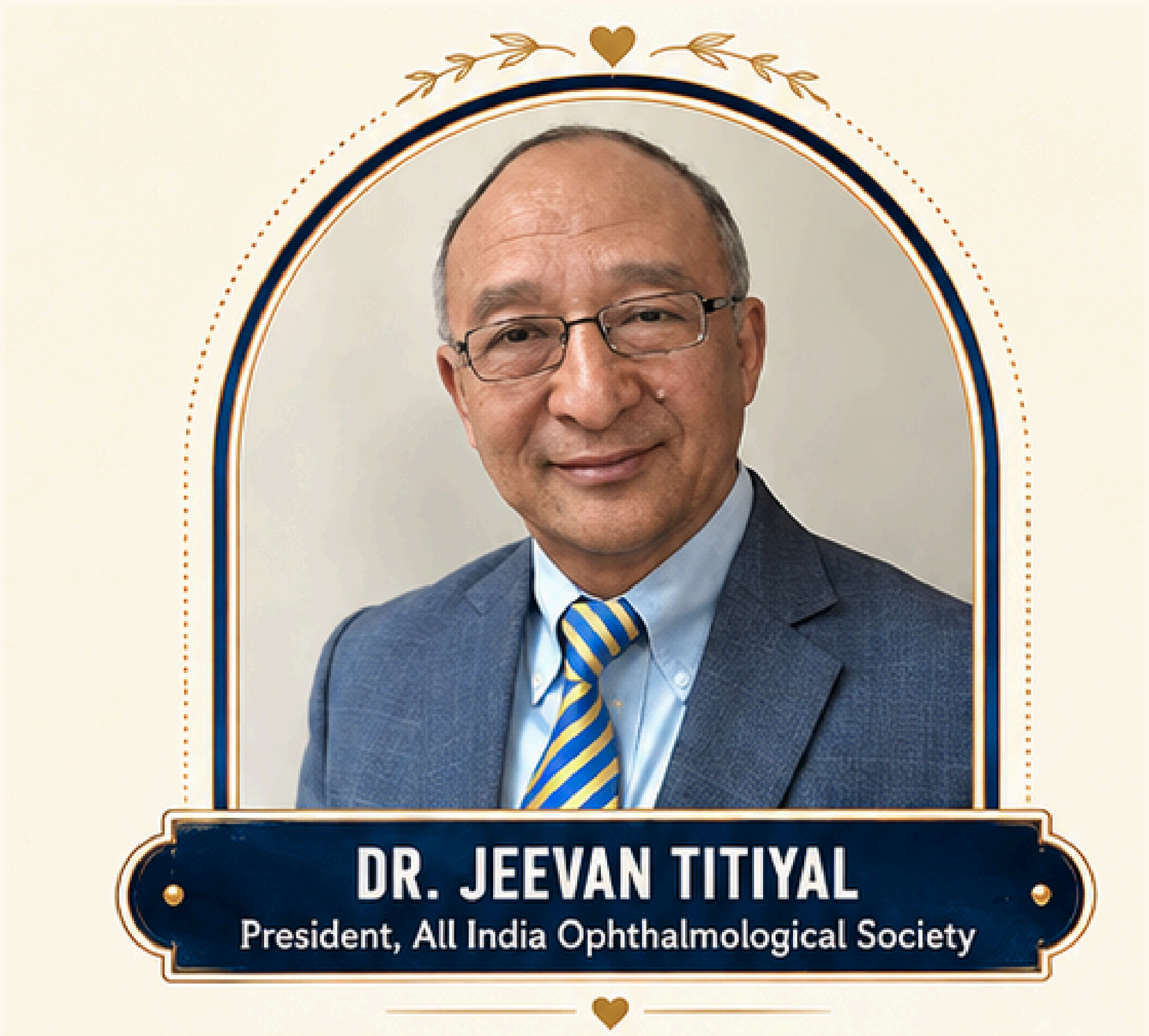
I would particularly like to acknowledge the role played by key professional groups and partners in this journey — the Indian Pediatric Hematology Oncology Group, the Indian Academy of Pediatrics and the pediatric community, and the All India Ophthalmological Society and the ophthalmology community.

I congratulate all of them, and I would also like to acknowledge the important role played by CanKids as the facilitator and secretariat of the Fight Retinoblastoma India movement.
I am especially pleased that the journey of Fight Retinoblastoma India has now been documented in the Indian Journal of Ophthalmology, one of the country's most respected peer-reviewed medical journals. This publication is important because it validates the Fight Retinoblastoma India model as a nationally and globally relevant example of stakeholder-led, patient-centered healthcare delivery in a low- and middle-income country setting.
It also brings scientific visibility to important concepts such as shared care, early detection, referral pathways, patient navigation, survivorship, and a family-centered approach.

As India now moves from access towards improved survival and quality outcomes, I understand that Fight Retinoblastoma India and its partners are advocating many important next steps. I request all of you to keep going, and I wish you the very best in all your endeavors.

I congratulate all participants of the National Retinoblastoma Conclave and extend my best wishes for the continued success of this important national movement. Together, let us ensure that every child with retinoblastoma in India has the opportunity not only to survive but to thrive.

MESSAGES FROM
NATIONAL LEADERS AND PARTNERS



DR. JEEVAN TITIYAL
President, All India Ophthalmological Society

During International Retinoblastoma Week, I extend my heartfelt congratulations to Fight Retinoblastoma India and all its partners on achieving an important national milestone — near-universal access to care for children with retinoblastoma across India.
Retinoblastoma is a rare but highly curable eye cancer of childhood. Early detection and timely referral can save not only life, but also vision and quality of life.
The ophthalmology community of India, through AIOS and its ocular oncology network, has played an important role in strengthening awareness, early detection, referral pathways, diagnosis, and treatment for children with retinoblastoma across the country.
Today, India has a collaborative network of 90 retinoblastoma treating centres integrating pediatric oncology and ocular oncology expertise, bringing expert care closer to children and families.
AIOS is proud to partner with Fight Retinoblastoma India, the pediatric oncology community, IAP, IAP-PHO, INPHOG, patient advocacy groups, and all stakeholders working together to improve outcomes for children with retinoblastoma.
I would especially like to congratulate Dr Santosh Honavar, Secretary of AIOS, whose visionary leadership, clinical excellence, research contributions, and commitment to collaboration have brought great laurels to India and played a transformative role in advancing retinoblastoma care nationally and internationally.
The publication of the Fight Retinoblastoma India journey in the Indian Journal of Ophthalmology is also a matter of pride for the ophthalmology community and demonstrates what can be achieved through stakeholder collaboration and patient-centred care.
As we move towards the next frontier — improved survival, vision preservation, and financial protection for every child — it is important that we continue to strengthen:

- awareness and red reflex screening,
- early diagnosis,
- referral systems,
- access to advanced therapies,
- and multidisciplinary collaboration.

Together, we can ensure that no child loses life or sight because of delay in diagnosis or lack of access to care.

India is fighting retinoblastoma — and we are winning.

MESSAGES FROM NATIONAL LEADERS AND PARTNERS



I would like to extend my heartfelt congratulations to the Fight Retinoblastoma team in India, all partner NGOs, CanKids chapters, the Ophthalmology Society, ophthalmologists, oncologists, policymakers, every stakeholder, and everyone who has contributed to achieving this wonderful milestone of near-universal access to care for children with retinoblastoma across India.

I am pleased to know that all patients with retinoblastoma can now be connected through a single directory where care is available for all. This is truly a stupendous achievement, and I believe it reflects the power of collaboration, awareness, early diagnosis, and a timely referral system that can not only help save the lives of children but also ensure timely treatment.

We all know the importance of screening, as prevention is always better than cure. Screening is essential, especially in newborns, whether we are talking about inborn errors of metabolism, hearing issues, eye conditions, or other congenital disorders. Even conditions such as congenital dislocation of the hip and other vision-related problems can be detected through screening. Screening also helps in identifying developmental delays and nutritional issues.

Therefore, it is extremely important to screen young babies. During this Retinoblastoma Week, I would like to emphasize what the WHO advocates—that three things should be universal for all children: hearing screening, eye screening, and bilirubin level assessment. Pediatricians play an extremely important role in early detection, and a simple red reflex screening using a torchlight or an ophthalmoscope during routine examinations can truly be life-saving. Through this test, not only can conditions such as cataracts be detected, but also retinoblastoma, where one may observe the cat-eye reflex or leukocoria—a white reflex instead of the normal red reflex.

I am happy to collaborate with other stakeholders during this Retinoblastoma Week to emphasize the importance of early screening among all pediatricians and healthcare workers. They should incorporate red reflex examination into their regular assessments so that they are able to diagnose potentially life-threatening conditions such as retinoblastoma in a timely manner. With the support of various stakeholders and professional societies, we can help these children receive the right treatment at the right time.

When I speak about stakeholders, I would especially like to congratulate Dr. Amita Mahajan for her outstanding contribution, not only as a pediatric oncologist but also for the special interest and dedication she has shown in supporting CanKids and the retinoblastoma initiative.

Let us continue to work together so that no child loses their life or vision due to the delayed diagnosis of retinoblastoma.

Once again, I, Dr. Neelam Mohan, would like to thank you all for giving me this opportunity to speak on behalf of the Indian Academy of Pediatrics, and I extend our continued commitment to this cause.

MESSAGES FROM NATIONAL LEADERS AND PARTNERS



DR. RAMANDEEP ARORA
President, Indian Pediatric Hematology Oncology Group

During International Retinoblastoma Week, I congratulate Fight Retinoblastoma India and all stakeholders on achieving an important national milestone — near-universal access to care for children with retinoblastoma across India.

This achievement reflects what is possible when clinicians, researchers, hospitals, pediatricians, ophthalmologists, patient advocacy groups, survivors, civil society organisations, and government partners work together with a shared purpose.
INPHOG is proud to partner with Fight Retinoblastoma India, AIOS, IAP, IAP-PHO, and the pediatric oncology community in strengthening collaborative research, registries, evidence generation, and standardized approaches to care for children with retinoblastoma.

One of the important milestones in this journey was the first collaborative multicentre retinoblastoma study undertaken through INPHOG in partnership with and supported by CanKids…KidsCan, involving 20 centres and more than 1120 children across India. This landmark effort demonstrated the power of collaborative research and shared learning in improving understanding and outcomes for retinoblastoma in India.

Building on this foundation, we are now moving towards strengthening collaborative registry-based research and data systems that can help improve survival, quality of care, referral pathways, and long-term outcomes for children with retinoblastoma nationally.

I would also like to acknowledge the important contributions of Dr Santosh Honavar, Dr Amita Mahajan, and the many clinicians and researchers across India whose collaborative work has helped strengthen retinoblastoma care nationally.
The publication of this journey in the Indian Journal of Ophthalmology is an important recognition of how science, systems, and stakeholder collaboration can work together to improve survival and vision outcomes.

As we move towards the next frontier — 100% financial protection and improved survival for every child — we must continue to strengthen:

- collaborative registries,
- implementation research,
- early detection pathways,
- and equitable access to quality treatment across India.

India is fighting retinoblastoma — and we are winning.

A HISTORIC MILESTONE

Milestones

2014 Launched Fight RB India – 2014

2019 Partnership with InPhog - First multicentric, prospective collaborative study from India for retinoblastoma 2019

2021 Genetic testing started

2024 Partnership with All India Ophthalmological Society (AIOS)

2025 Partnership with Indian Academy of Pediatrics (IAP)

2026 Near universal access to RB care



Achievements

90
Retinoblastoma treatment centres

134
Health professionals
Ophthalmology + Ocular Oncology + Pediatric Oncology

1664
access to care

Coverage across **28** states and **8** union Territories

National Stakeholder platform

Collaborative research network

Sophisticated therapeutic interventions-
Brachytherapy, Intra arterial chemotherapy (IAC), Genetic Testing

16,000+
Government health Professional sensitized about RB

First Childhood Cancer - near universal access to care

12th
Fight RB India stakeholder meeting held under the banner of ISOO

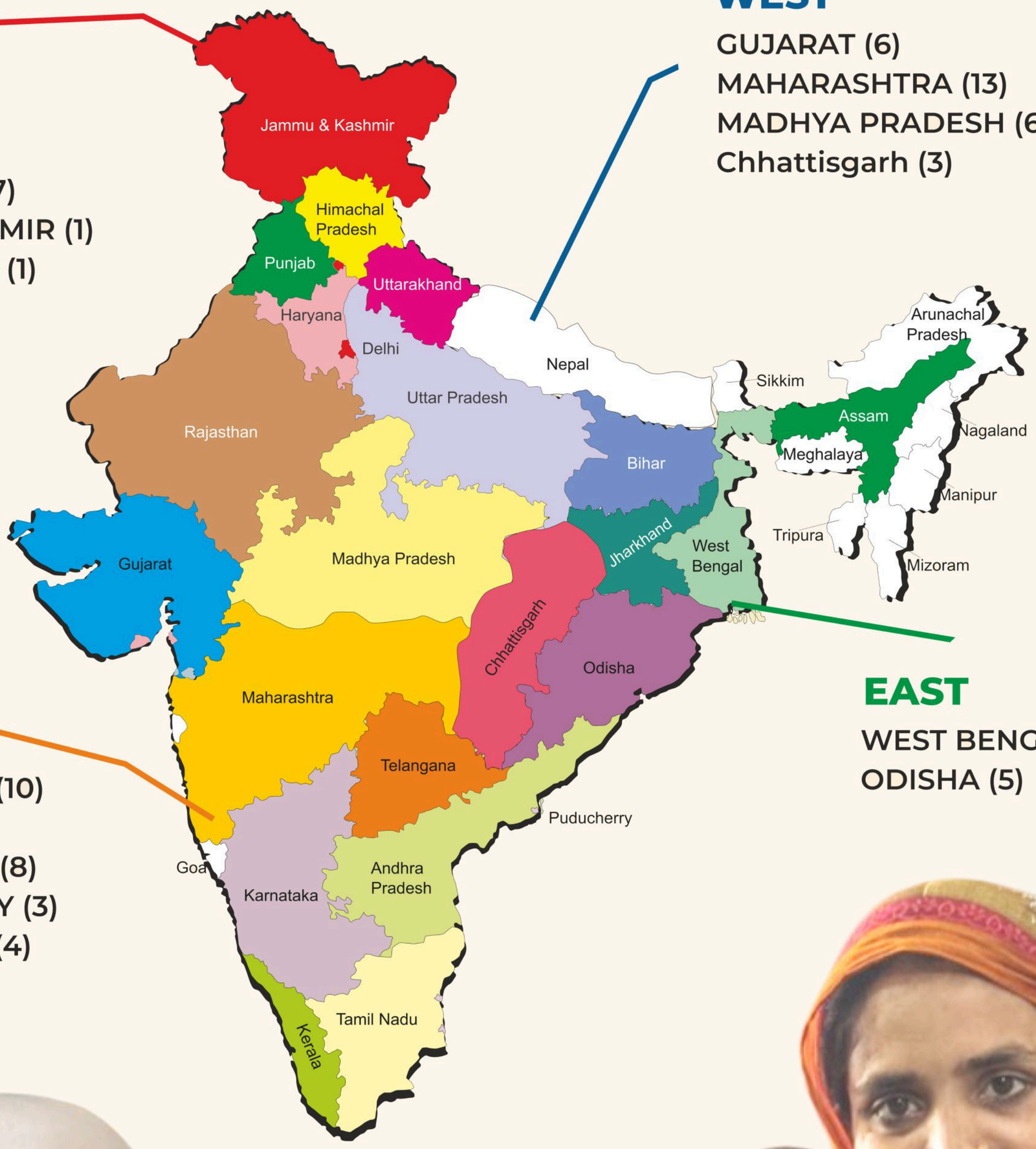
NEAR - UNIVERSAL ACCESS TO RETINOBLASTOMA CARE IN INDIA

NORTH

DELHI (6)
RAJASTHAN (3)
PUNJAB (3)
Uttar Pradesh (7)
JAMMU & KASHMIR (1)
UTTARAKHAND (1)
HARYANA (1)
BIHAR (3)

WEST

GUJARAT (6)
MAHARASHTRA (13)
MADHYA PRADESH (6)
Chhattisgarh (3)



SOUTH

KARNATAKA (10)
KERALA (4)
TAMIL NADU (8)
PUDUCHERRY (3)
TELENGANA (4)

EAST

WEST BENGAL (8)
ODISHA (5)





ANCHORED BY LIVED EXPERIENCE

How Survivors and Parents Shaped the National Conclave

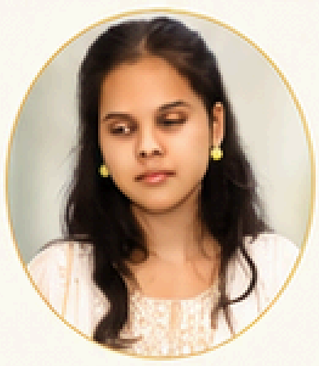
Speaking with patients and families — not just about them.

The Conclave was built on a simple but powerful choice: to speak with patients and families — not just about them. Our Survivor Ambassadors and Parent Advocate were at the heart of every conversation.

They guided discussions, introduced speakers, moderated sessions, challenged assumptions, and brought lived experience into the room. Their journeys grounded our deliberations in what matters most — the lives and futures of children affected by Retinoblastoma.

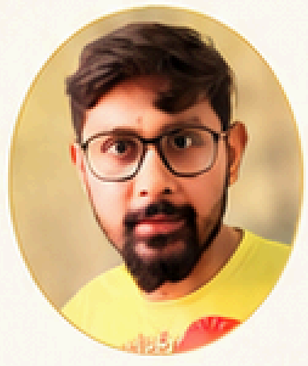


> From the opening **prayer by survivor Janki Gupta,** to the **moderation by** survivor ambassadors **Atul Rathod, Preeti Phad, Shivam Dubey, Vikash Yadav** and **parent advocate Priti Rastogi,** the conclave demonstrated that meaningful patient-centred care is not merely about designing services around patients — it is about ensuring that their voices are heard, their experiences shape decisions, and their leadership helps guide the future of care.



JANKI GUPTA | Retinoblastoma Survivor

A Retinoblastoma survivor who commenced the conclave with a soulful Saraswati Vandana. Her performance reflected resilience, determination, hope, courage, and the pursuit of dreams despite adversity. She reminded participants that cancer should never limit a child's potential or aspirations.



VIKASH YADAV | Survivor Ambassador

A Retinoblastoma survivor from Uttar Pradesh who shared his journey through delayed diagnosis, multiple surgeries, chemotherapy, and radiation. Supported by CanKids and KidsCan Konnect, he continued his education, completed an MBA in Social Entrepreneurship, and has worked with CanKids for six years. As a survivor advocate, he emphasized early diagnosis, timely referral, affordable treatment, financial protection, and survivor-centred care. He stressed that every child deserves not only survival but also the opportunity to rebuild life and pursue dreams.



ATUL RATHOD | Survivor Ambassador

A Retinoblastoma survivor and survivor leader, diagnosed at age two, who completed treatment with strong support from his mother and CanKids. Today he serves as Secretary of KidsCan Konnect and works in Strategic Communication and Youth Engagement at CanKids. He highlighted survivorship, peer support, and patient-centred care, emphasizing dignity, opportunity, and a hopeful future for every child.



PREETI PHAD | Survivor Ambassador

A Retinoblastoma survivor and Manager of UGAM at the Indian Cancer Society. She reflected on delayed diagnosis, intensive treatment, and the challenges of life after cancer, She described transforming fear, uncertainty, and stigma into advocacy and patient-centred care. She continues to champion the voices of childhood cancer survivors and families, highlighting India's progress from fragmented systems to a nationwide movement built on collaboration, evidence-based care, survivor leadership, and hope.



SHIVAM DUBEY | Survivor Ambassador

A Survivor Ambassador who moderated sessions with sensitivity and insight, ensuring meaningful dialogue and strong representation of patient voices throughout the conclave.



PRITI RASTOGI | Parent Ambassador

A parent of a child with RB and a parent advocate. She shared the emotional, financial, and logistical challenges families face after a Retinoblastoma diagnosis. She emphasized the importance of support systems, survivor networks, healthcare professionals, and patient organization in helping families navigate uncertainty and access timely care. She underscored how collective efforts have transformed individual struggles into a national movement committed to timely diagnosis, treatment, and the best possible chance of survival.

CHAPTER 1

Welcome
And Celebrating Life

The National Retinoblastoma Conclave commenced with an inspiring and heartfelt session, "Welcome & Celebrating Life," beautifully anchored by Retinoblastoma survivors Priti Phad and Atul Rathod. As confident survivor advocates, they brought warmth, energy, and authenticity to the event, skillfully guiding the audience through the proceedings.

Their personal journeys of resilience and hope served as a powerful reminder of what is possible through timely diagnosis, quality care, and continued support. By anchoring the entire conclave, Priti and Atul embodied the spirit of survivorship, inspiring participants and celebrating the achievements of the Retinoblastoma community.



Preeti Phad,
RB Ambassador



Atul Rathod,
RB Ambassador

The Session began with
lamp lighting ceremony,

commenced by Saraswati Vandana by **Janki Gupta,** a RB Survivor,

whose journey showed how music became a source of strength during her cancer journey emphasizing that childhood cancer should never take away a child's dreams.



Janki Gupta
RB Survivor

CHAPTER 2

FIGHT RB INDIA: A DECADE OF COLLECTIVE ACTION (2014–2026)



SESSION INFORMATION

Session	Journey So Far – India is Fighting RB and We Are Winning
Conclave Session	Session 1
Moderators	Priti Rastogi and Dr. Haresh Gupta
Survivor Anchors	Atul Rathod and Preeti Phad
Focus	A Decade of Progress, Stakeholder Collaboration, Survivor and Parent Perspectives, Validation of Near-Universal Access
Featured Presentation	Fight RB India: From Challenge to National Movement – Poonam Bagai

WHY FIGHT RB INDIA WAS CREATED

Born from the need to address critical gaps in Retinoblastoma care, Fight RB India has grown into a nationwide movement advancing awareness, timely diagnosis, quality treatment, research, collaboration, survivorship and advocacy—ensuring that every child with Retinoblastoma has the best chance of survival and a life of dignity.

VOICES THAT SHAPED THIS SESSION:

Poonam Bagai, Dr. Haresh Gupta, Priti Rastogi, Dr. Santosh Honavar, Kanaka Sirpal & Siddhant Sirpal, Fight RB India Founding Stakeholders

1 SURVIVOR & FAMILY VOICES

- Facilitators: Priti Phad and Atul Rathod (RB Survivors)

The session celebrated the role of survivors and families as key stakeholders in the Retinoblastoma movement.

- Priti Rastogi (Parent Advocate) shared the emotional, financial, and social challenges faced by families following an RB diagnosis, emphasizing the importance of community support, advocacy, rehabilitation, survivorship care, and dignity for every child and family.
- Dr. Haresh Gupta (Deputy CEO, CanKids KidsCan) reflected on the evolution of Fight RB India from 20 institutions in 2014 to nearly 90 treatment centres today, highlighting the power of collective action and collaboration in transforming Retinoblastoma care across India.

2 KEY PRIORITIES IDENTIFIED THROUGH THE MENTIMETER SESSION

The interactive discussion highlighted the following priority areas for strengthening the Retinoblastoma ecosystem:

- Delayed diagnosis and lack of awareness remain the most significant challenges in RB care.
- Diagnostic delays occur primarily at the family and community level, underscoring the need for stronger awareness and early recognition systems.
- Greater emphasis is needed on training community and healthcare workers for timely identification and referral.

Future efforts should focus on:

- Early detection systems,
- Awareness and stakeholder engagement,
- Strengthening treatment infrastructure,
- Improved service delivery and supportive care,
- Advancing the One Cancer at a Time – Retinoblastoma approach.

3 RECOGNIZING COLLABORATION & PARTNERSHIPS

- Poonam Bagai acknowledged the invaluable support of Ms. Kanaka Sirpal and Siddhant Sirpal for their continued commitment to advancing the Fight RB India mission.
- She also recognized Dr. Amita Mahajan's leadership in strengthening national standardization efforts through collaborative InPHOG initiatives, including treatment protocols, research, genetic testing support, and pathology and radiology standardization.
- The role of AIOS was highlighted as a critical platform for:
  - National advocacy,
  - Professional training and capacity building,
  - Strengthening regional ophthalmic care systems,
  - Promoting equitable access to Retinoblastoma care across India through its extensive professional network of over 26,700 members.

CHAPTER 3

PARTNERSHIPS AND COLLABORATIONS

Science • Systems • Shared Care



SESSION INFORMATION

Session	:	Partners & Collaborations – Science, Systems and Shared Care
Conclave Session	:	Session 2
Moderators	:	Preeti Phad RB Survivor, ICS Ugam, Mumbai and Dr. Manas Kalra, Former Secretary IAP PHO
Focus	:	Collaborative Research, Shared Care, Professional Partnerships, Capacity Building and Systems Strengthening
Featured Speakers	:	Dr. Jeevan Titiyal, Dr. Neelam Mohan, Dr. Ramandeep Arora, Dr. Amita Mahajan
Special Launch	:	Retinoblastoma Resource & Centres Directory
Key Outcome	:	Demonstration of how collaboration between AIOS, IAP, InPHOG, CanKids and healthcare institutions helped strengthen access, quality and continuity of Retinoblastoma care across India

VOICES THAT SHAPED THIS SESSION

Preeti Phad, Dr. Manas Kalra, Dr. Jeevan Titiyal, Dr. Neelam Mohan, Dr. Ramandeep Arora, Dr. Amita Mahajan

> "The progress achieved in Retinoblastoma care over the past decade would not have been possible without strong partnerships and collaborative leadership."

PARTNERSHIP PILLARS

1 All India Ophthalmological Society (AIOS)

AIOS has played a critical role in awareness generation, early detection, referral strengthening, professional education, and the development of ocular oncology services.

2 Indian Academy of Pediatrics (IAP)

Pediatricians remain the first point of contact for many children with Retinoblastoma. IAP's partnership has strengthened awareness, early diagnosis, red reflex screening, and referral pathways.

3 Indian Pediatric Hematology Oncology Group (InPHOG)

InPHOG has helped strengthen collaborative research and evidence generation, most notably through the InPOG-RB-19-01 collaborative study involving more than 1,120 children across 20 centres.

4 National Health Authority (NHA)

The NHA continues to play a critical role in strengthening financial protection and exploring opportunities to improve access to advanced therapies through public health financing mechanisms.

5 NITI Aayog

NITI Aayog has recognized the Fight RB India journey as a model of stakeholder collaboration and patient-centred healthcare.

6 Survivors and Parent Advocates

The survivor and parent movement remains one of the strongest pillars of Fight RB India, ensuring that lived experience informs policy, programmes, and systems development.

CHAPTER 4

PUBLICATIONS, LAUNCHES AND MILESTONES

Celebrating knowledge, visibility, advocacy and national progress.

The National Retinoblastoma Conclave 2026 marked several important national milestones.
These achievements strengthen research, expand collaboration, empower communities and drive equitable access to care for every child.

> A decade of progress.
> A new era of visibility, access and action.

1 INDIAN JOURNAL OF OPHTHALMOLOGY PUBLICATION

The conclave celebrated the publication documenting India's decade-long Retinoblastoma journey and the collective efforts that contributed to improving access, collaboration, and patient-centred care.

2 RETINOBLASTOMA RESOURCE AND CENTRES DIRECTORY

The directory was launched to support families, clinicians, and referral networks in identifying appropriate centres and improving access to specialized care.

3 NATIONAL APPEAL FILM

The conclave premiered:
'Mr Prime Minister –
Do You See What EYE See?'
The film calls for stronger national action on early diagnosis, financial protection, access to advanced therapies, and improved survival outcomes.

4 VALIDATION OF NEAR-UNIVERSAL ACCESS

Perhaps the most significant milestone celebrated during the conclave was the validation of near-universal access to Retinoblastoma care in India — a landmark achievement for childhood cancer care in the country.



National Retinoblastoma Conclave Report 2026

CHAPTER 5

THE NATIONAL ASK

From Access to Financial Protection and Survival

- The National Retinoblastoma Conclave 2026 celebrated a major milestone in India's childhood cancer journey: near-universal access to Retinoblastoma care. Yet stakeholders agreed that access alone is not enough.
- The next phase of India's journey must focus on ensuring that every child not only reaches treatment but also completes treatment, survives, preserves vision wherever possible, and receives comprehensive support throughout the continuum of care.
- The conclave therefore articulated a collective National Ask focused on strengthening policy, financing, service delivery, and survivorship through this film.

Session: The National Ask – From Access to Financial Protection and Survival

Conclave Session: Session 3

Moderators: Poonam Bagai and Vikas Yadav

Focus: Universal Health Coverage, Financial Protection, Advanced Therapies, Centres of Excellence and Survival Outcomes

Featured Film: Mr. Prime Minister – Do You See What EYE See?

Government Leaders: Dr. Pankaj Arora, National Health Authority; Dr. M. Srinivas, NITI Aayog

Key Outcome: Consensus on the need to move from access to improved survival, financial protection, advanced treatment access and patient-centred healthcare systems



MR. PRIME MINISTER, DO YOU SEE WHAT EYE SEE?

A National Appeal for Every Child with Retinoblastoma

In the Film:

- India has demonstrated that collaborative action can achieve near-universal access to Retinoblastoma care.
- The next challenge is survival.
- The next challenge is vision preservation.
- The next challenge is financial protection.
- The next challenge is ensuring that no child loses sight, treatment, or life because of where they live or what their family can afford.

> *The question before us is no longer whether children can access care. The question is whether every child can access the right care, at the right time, without financial hardship.*
>
> — Fight RB India National Conclave 2026





Moderators Poonam Bagai and Vikas Yadav guiding the session with insight and empathy.

1 Ask 1: Universal Health Coverage for Every Child with Retinoblastoma

While significant progress has been made in expanding access, many families continue to face financial hardship during treatment. Stakeholders called for strengthening Universal Health Coverage mechanisms to ensure that no child is denied treatment because of financial barriers.

Priorities include:

- Comprehensive coverage across the treatment continuum
- Reduction of out-of-pocket expenditure
- Improved support for diagnostics and supportive care
- Financial protection for vulnerable families
- Reduction of treatment abandonment related to economic hardship

2 Ask 2: Inclusion of Advanced Therapies

India has witnessed major advances in eye-salvage therapies over the last decade.

Stakeholders emphasized the need to strengthen access to:

- Intra-Arterial Chemotherapy (IAC)
- Intravitreal Chemotherapy (IVC)
- Brachytherapy
- Advanced focal therapies
- Genetic testing and counselling

The conclave recommended review of existing reimbursement mechanisms to better reflect the realities of modern Retinoblastoma care.

3 Ask 3: National Retinoblastoma Helpdesk and Patient Navigation System

Families frequently struggle with:

- Identifying appropriate treatment centres
- Understanding treatment pathways
- Accessing financial support
- Coordinating referrals
- Navigating survivorship services

Stakeholders recommended strengthening a National Retinoblastoma Helpdesk and Patient Navigation System capable of supporting families throughout their journey.



✦ **Dr. Pankaj Arora,** National Health Authority, addressing the conclave.



✦ **Dr. M. Srinivas,** NITI Aayog, addressing the conclave virtually.

The National Ask now moves from identifying the challenge to articulating concrete priorities for the next phase of India's Retinoblastoma journey.

> "The ultimate goal is not only access. The ultimate goal is survival, vision preservation, rehabilitation and the opportunity for every child to thrive."

4 Ask 4: Centres of Excellence and Shared Care Networks

The conclave emphasized the need to define national criteria for Retinoblastoma Centres of Excellence. Such centres should provide:

- Multidisciplinary care
- Advanced diagnostics
- Ocular oncology expertise
- Access to advanced therapies
- Research and training functions
- Referral support

These centres should function within regional hub-and-spoke networks to ensure equitable access across India.

5 Ask 5: Early Detection and Timely Referral

Delayed diagnosis remains one of the greatest threats to survival and vision preservation. The conclave recommended:

- Integration of red reflex screening into child health services
- Greater engagement of pediatricians
- Training of frontline healthcare workers
- Strengthening referral pathways
- Public awareness on leukocoria and childhood eye abnormalities

6 Ask 6: Research, Registries and Data-Driven Care

India's collaborative research efforts have already demonstrated the value of multicentric studies and shared learning. The conclave recommended:

- Strengthening national registries
- Expanding collaborative research
- Tracking survival outcomes
- Monitoring treatment abandonment
- Generating evidence for policy and financing decisions

7 Ask 7: Survivorship and Rehabilitation

The ultimate goal is not only survival. Children must also have opportunities to learn, grow, participate, and thrive. Stakeholders emphasized:

- Rehabilitation services
- Vision support
- Educational continuity
- Psychosocial care
- Career guidance
- Long-term follow-up

The National Ask therefore extends beyond healthcare to encompass the broader rights and future of every child affected by Retinoblastoma.

From access to survival. From treatment to thriving.

CHAPTER 6

2030 GOALS – THE WAY FORWARD

SESSION INFORMATION

Session	2030 Goals – The Way Forward
Conclave Session	Session 4
Moderators	Shivam Dubey, and Dr Nishant Verma
Focus	Vision 2030 shifts the focus from access to outcomes—saving lives, preserving vision, and improving quality of life for every child with Retinoblastoma.
Featured Speakers	Shivam Dubey, Dr Nishant Verma, Dr. Santosh Honavar, Dr. Amita Mahajan, Dr. Neelima Thakur
Key Outcome	Stakeholders endorsed a shared roadmap to achieve higher survival, better vision outcomes, equitable care, financial protection, and strengthened survivorship support by 2030.

VISION 2030
FROM ACCESS TO SURVIVAL
Save Lives - Save Eyes - Save Vision

- The validation of near-universal access to Retinoblastoma care marks the completion of one chapter in India's journey.
- Vision 2030 defines the next.
- The challenge before the Retinoblastoma community is to transform access into outcomes and ensure that every child benefits from timely diagnosis, quality treatment, financial protection, rehabilitation, and survivorship support.

VISION 2030 GOALS

SURVIVAL
Achieve 80–90% survival for children with Retinoblastoma across India.

FINANCIAL PROTECTION
Reduce the financial burden of treatment on families.

EYE SALVAGE
Maximize opportunities for eye preservation wherever clinically feasible.

SURVIVORSHIP
Strengthen rehabilitation, psychosocial support, education continuity, and long-term follow-up.

VISION PRESERVATION
Improve visual outcomes through timely diagnosis and appropriate intervention.

RESEARCH AND INNOVATION
Expand collaborative research and data-driven planning.

EQUITABLE ACCESS
Ensure that geography, income, gender, and social circumstances do not determine outcomes.

CAPACITY BUILDING
Strengthen workforce development and multidisciplinary expertise.

A CONTINUUM OF CARE

Vision 2030 recognizes that Retinoblastoma care does not begin at diagnosis and does not end with treatment.
The future system must support children through:

Early Detection → Diagnosis → Referral → Treatment → Rehabilitation → Survivorship → Reintegration

EVERY STEP MATTERS.

A SHARED COMMITMENT

The Vision 2030 roadmap reflects the collective commitment of clinicians, survivors, parents, professional societies, policymakers, healthcare institutions, civil society organizations, and donors.
Together, these stakeholders will continue to work toward a future where every child diagnosed with Retinoblastoma has the opportunity to survive, preserve vision wherever possible, and live a healthy and productive life.


SHIVAM DUBEY



DR. SANTOSH HONAVAR


DR. NEELIMA THAKUR


SHIVAM, DR. SANTOSH HONAVAR & DR. NISHANT VERMA

CHAPTER 7

HONOURING SURVIVORS, PARENTS AND STAKEHOLDERS

Recognition • Gratitude • Survivor Leadership • Collective Achievement

SESSION INFORMATION

Session	:	Honouring the Movement – Survivors, Stakeholders and Champions
Conclave Session	:	Closing Recognition Ceremony
Facilitators	:	Fight RB India Secretariat
Focus	:	Recognition, Gratitude, Survivor Leadership and Collective Achievement
Honourees	:	Survivors, Parents, Clinicians, Researchers, Professional Bodies, Partners and Donors
Key Outcome	:	Celebration of the collective stakeholder movement that has transformed Retinoblastoma care in India and reaffirmed commitment to Vision 2030

Voices that Shaped this Session: Dr. Neelima Thakur and Poonam Bagai

The National Retinoblastoma Conclave 2026 was above all a celebration of people. Behind every milestone, every publication, every policy recommendation, and every treatment centre stand individuals whose commitment has transformed Retinoblastoma care across India. This chapter honours those individuals and institutions.



HONOURING SURVIVOR LEADERS ★

Special recognition was accorded to survivor ambassadors whose courage, leadership, and advocacy continue to inspire families across the country. Their journeys demonstrate that survivorship is not merely about overcoming cancer but about rebuilding confidence, pursuing education, establishing careers, supporting others, and creating hope.

- ★ **Atul Rathod**
- ★ **Preeti Phad**
- ★ **Vikas Yadav**
- ★ **Shivam Dubey**
- ★ **Janki Gupta**

whose leadership throughout the conclave embodied the principle of patient-centred care.



HONOURING PARENT ADVOCATES ★

The conclave also recognized the extraordinary role played by parents who transform personal adversity into advocacy and support for others. Special appreciation was extended to **Priti Rastogi,** and to parent leaders across India who continue to guide newly diagnosed families and strengthen the Fight RB India movement.



HONOURING CLINICIANS AND HEALTHCARE INSTITUTIONS

The progress achieved over the past decade would not have been possible without the dedication of ophthalmologists, pediatric oncologists, pathologists, radiologists, nurses, counsellors, and multidisciplinary care teams. The conclave acknowledged healthcare institutions and professionals who have contributed to improving diagnosis, treatment, research, training, and patient support.



HONOURING PARTNERS AND PROFESSIONAL SOCIETIES

Recognition was extended to:

- All India Ophthalmological Society (AIOS)
- Indian Academy of Pediatrics (IAP)
- Indian Pediatric Hematology Oncology Group (InPhOG)
- National Health Authority (NHA)
- NITI Aayog

and other collaborating organizations whose partnership has strengthened the national Retinoblastoma ecosystem.



HONOURING DONORS AND SUPPORTERS

The Fight RB India movement has been sustained by individuals, institutions, philanthropists, and donor partners who believed in the vision of improving outcomes for children with Retinoblastoma. Their support has enabled awareness initiatives, research, patient navigation, rehabilitation services, capacity building, and advocacy efforts across India.



TOGETHER WE HAVE MADE HISTORY

The validation of near-universal access to Retinoblastoma care is not the achievement of any one institution or individual. It is the achievement of an entire community united by a shared commitment to children and families. As India moves toward Vision 2030, this collective spirit remains the movement's greatest strength.

Together, we have made history.
Together, we will build the future.

HONOURING CHAMPIONS OF CHANGE



CANKIDS KIDSCAN — National Society for Change for Childhood Cancer in India

Fight RB, India — RB India National Stakeholder Group

THE SAJIV CANKIDS RETINOBLASTOMA FUND

A Legacy of Hope, Sight & Survival

CERTIFICATE

OF GRATITUDE & IMPACT

Presented to

Kanaka Sirpal & Siddhant Sirpal

and in loving memory of

Sajiv Sirpal

For over a decade of extraordinary philanthropy through the Sajiv CanKids Retinoblastoma Fund.

Your unwavering commitment has helped transform Retinoblastoma care in India, strengthening treatment centres, empowering families, advancing collaboration, and helping India achieve near-universal access to care for children with Retinoblastoma.

Together, we have helped save lives, save eyes, preserve vision, and create hope for thousands of children and families.

India is Fighting Retinoblastoma And We Are Winning!

Your Family Helped Make History.

90
RETINOBLASTOMA TREATMENT CENTRES

NEAR-UNIVERSAL
ACCESS TO CARE

THOUSANDS
OF CHILDREN SUPPORTED

Poonam Bagai
Poonam Bagai
Founder Chairman
CanKids KidsCan

Santosh Honavar
Dr. Santosh Honavar
International Ocular Oncologist,
Cheif Architect, Fight RB India

Amita Mahajan
Dr. Amita Mahajan
Senior Pediatric Oncologist
& Lead Suddhridh OCAT Project








constitution
club of india
National Society
for Change for
Childhood Cancer


STORIES OF RETINOBLASTOMA SURVIVORS
Not stories of loss — stories of courage, survival and dreams.
Retinoblastoma changed their journey, but not their future. With timely treatment, family strength and support, these survivors continu
SAVE LIVES | SAVE EYES | SAVE VISION
Parth Prakash Shinde
Survivor | B.Tech Student – AI & Data Science
Preeti Phad
Survivor | Survivorship Advocate | Manager, UGAM – ICS
Anand Singh
Survivor | Assistant Manager, IDBI Bank




INDIAN ACADEMY OF PEDIATRICS
A HISTORIC


Tech Support
Gupta
Dr priyanka

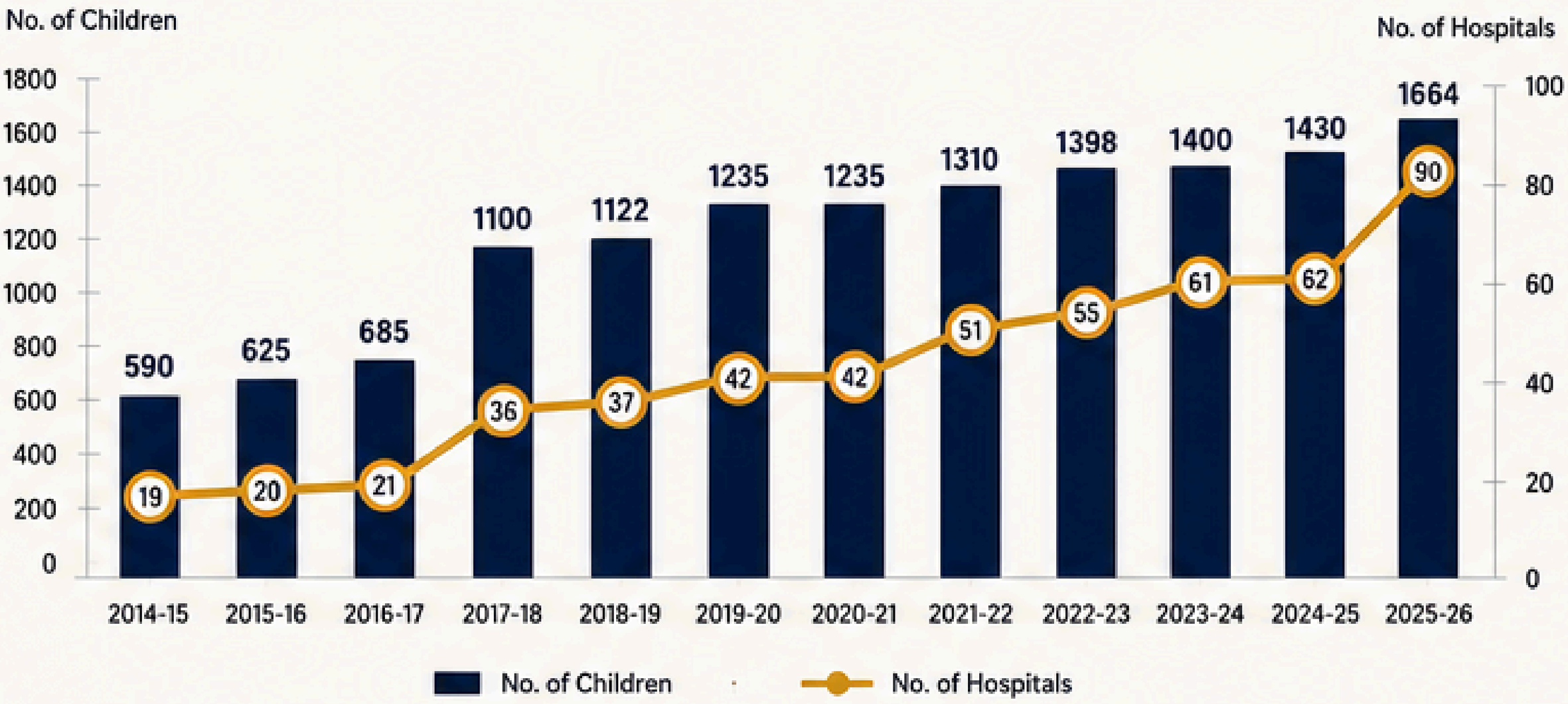


DATA VALIDATION FOR RB

ACCESS TO CARE HAS INCREASED DRAMATICALLY

- Estimated annual incidence = 1,676
- Children reaching treatment centres: 1664
- Access to care: 99.2%

YEAR WISE ACCESS WITH HOSPITALS FROM 19 TO 90 CENTERS



THE VALIDATION EXERCISE

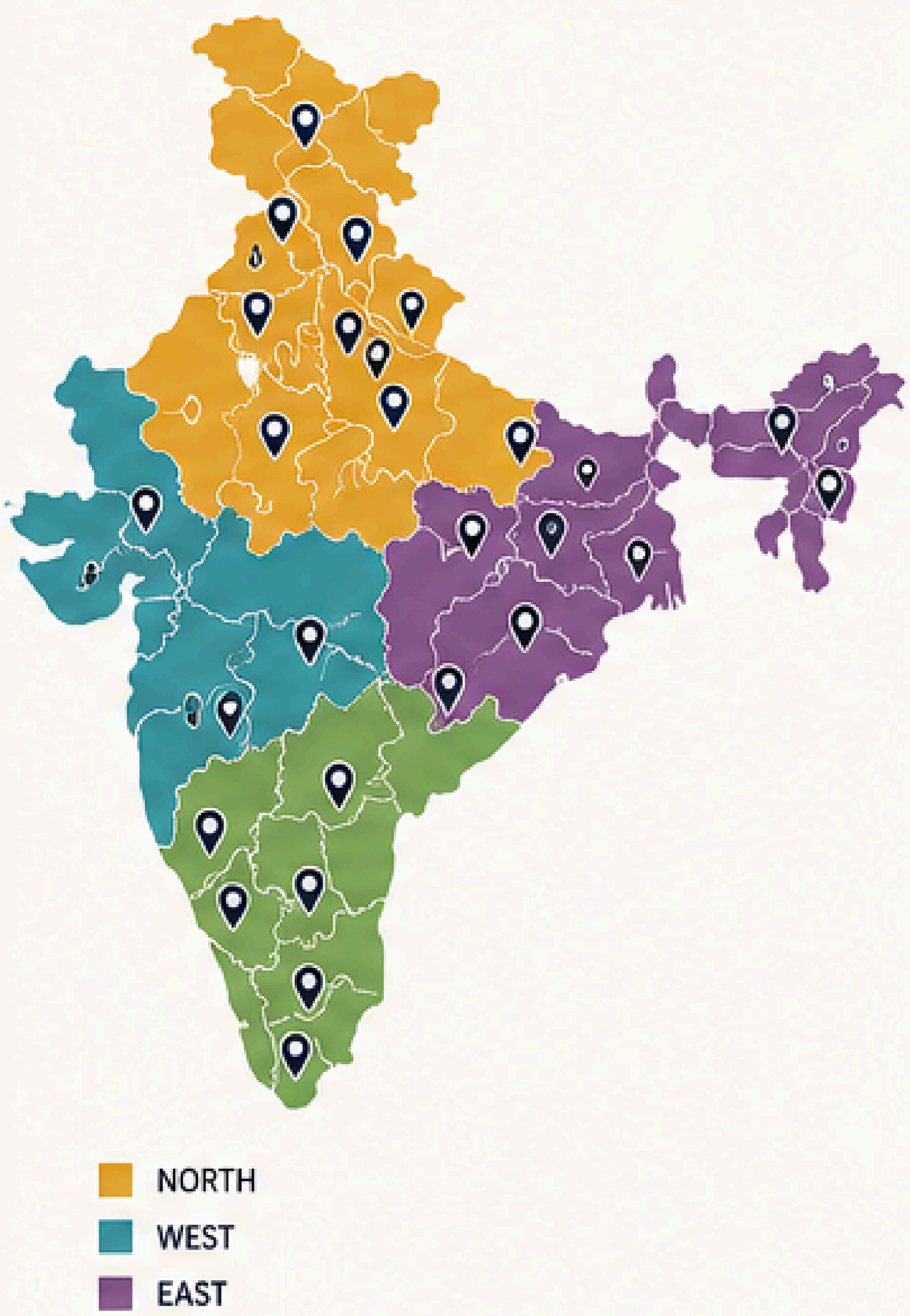
In preparation for the 14th Fight RB India Stakeholder Meeting, stakeholders undertook a national mapping and validation exercise to assess whether children with Retinoblastoma across India had access to specialized diagnosis and treatment services.

THE EXERCISE REVIEWED:

- TREATMENT CENTRES
- GEOGRAPHIC COVERAGE
- REFERRAL PATHWAYS
- SPECIALIST AVAILABILITY
- REGIONAL ACCESS GAPS
- PATIENT NAVIGATION SYSTEMS

WHAT THE STAKEHOLDERS VALIDATED

EVERY REGION OF INDIA NOW HAS ACCESS TO SPECIALIZED RETINOBLASTOMA CARE



REGION	INCIDENCE*	NO. OF HOSPITALS	PATIENTS ACCESSING CARE IN THE RB HOSPITALS IN STATE (AS PER FOLLOW-UP FROM THE CENTERS)
EAST	287	13	162
NORTH	745	24	589
SOUTH	284	25	614
WEST	360	28	299
TOTAL	1676	90	1664

** Estimated annual incidence*

VALIDATION STATEMENT

Following review of the national treatment network, geographic distribution of centres, referral pathways, specialist availability and patient access patterns, stakeholders concluded that India has achieved **near-universal access to specialized Retinoblastoma care.**

Annexure 1

Network of Retinoblastoma Treatment Centres (2026)

Region	State	Sr. No.	Hospital Name
East	Assam	1	Shri Sankaradeva Nethralaya Guwahati
			Dr. B Borooah Cancer Institute Guwahati
		2	Assam medical College
		3	Cachar Cancer Hospital
	Jharkhand	4	Pals Retina Care Ranchi
	Odisha	5	LVPEI Bhubaneswar
			Sparsh Hospital
		6	Vssimsar burla
		7	Veer Surendra Sai Institute of Medical Science & Research (VIMSAR) Burla
		8	All India Institute of Medical Sciences, Bhubaneswar
	West Bengal	9	Sankara Nethralaya Kolkata
			Tata Medical Center, Kolkata
		10	Susrut Eye Foundation &Research Centre
			Tata Medical Center, Kolkata
		11	Regional Institue of Opthalmology, Kolkata
			Medical college kolkata (Dep. Of Oncology)
		12	Noor Eye Care kolkata
		13	SGCC&RI Thakurpukar
North	Delhi	14	Dr. B.R.A Institute-Rotary Cancer Hospital (IRCH)
			R.P Center, AIIMS
			Peadriatic Oncology Department, AIIMS
		15	Dr. Shroff Charity Eye Hospital, Delhi
			Apollo Hospital Delhi
		16	Maulana Azad Medical College/ LNJ Hospital
		17	MAX Hospital Saket
		18	View Care
		19	AIIMS-CAPFIMS
	Bihar	20	Indira Gandhi Institute of Medical Sciences, Patna
		21	AIIMS Patna
		22	Mahavir Cancer Sansthan, Patna
	Punjab	23	Post Graduate Institute of Medical, Education & Research, Chandigarh
		24	AIIMS BATHINDA
		25	Government Medical College & Hospital Chandigarh
	Rajasthan	26	Sawai Man Singh Hospital, Jaipur
		27	PBM hospital Bikaner (ATRCC)
		28	MGM , Jaipur
	Harayana	29	SHKM GMC NUH
	J&K	30	AIIMS Jammu
	Uttar Pradesh	31	King George's Medical University, Lucknow
		32	Ram Manohar Lohia, Lucknow
		33	Banaras Hindu University (Peadriatic Oncology)
		34	Homi Bhabha Cancer Hospital Varanasi
		35	Sankara eye hospital, Varanasi
		36	Kamala Nehru Memorial Hospital
		37	Sitapur Eye Hospital

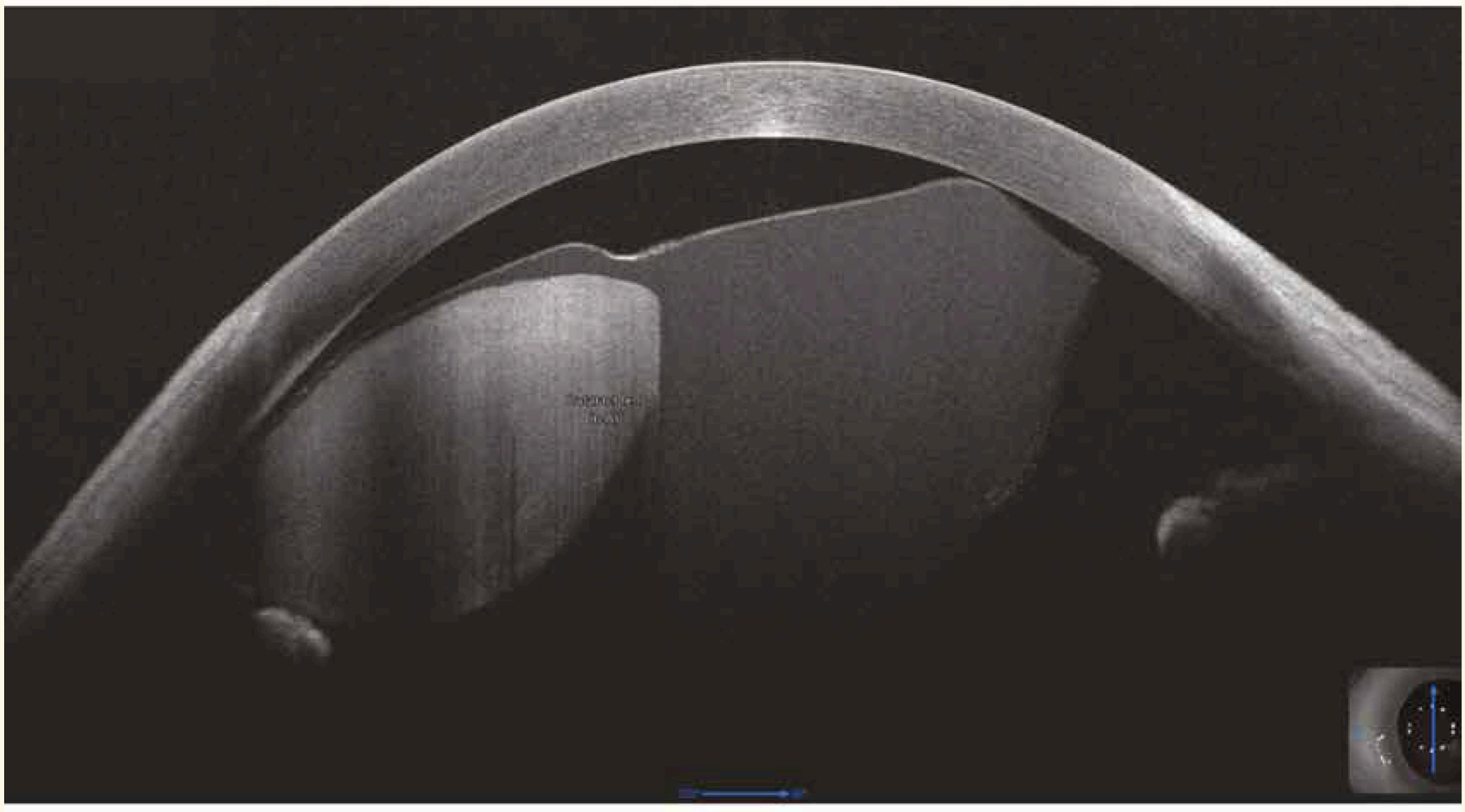
Annexure 1

Network of Retinoblastoma Treatment Centres (2026)

Region	State	Sr. No.	Hospital Name
South	Karnataka	38	Sankara Eye Hospital Banglore
		39	NH Banglore
			Narayana Netryalaya NHBanglore
		40	Prabha Eye Clinic
		41	A J INSTITUTE OF MEDICAL SCINECES AND RESEARCH CENTER, MANGALORE
		42	St John's Medical College Hospital
		43	GOVT GENERAL HOSPITAL SUBDISTRICT GULBARGA
		44	Yenepoya medical college and hospital
		45	Regional Institute of Ophthalmology, Minto Ophthalmic Hospital, Bangalore
		46	Kidwai Memorial Institute of Oncology
	Kerala	47	MVRCCRI, Poolacode, KozhikodeKerala
		48	Comtrust Eye Hospital, Kozhikode, Kerala
		49	RCC Trivandrum
		50	Chaithanya Eye Hospital, Trivandrum
	Puducherry	51	Aravind Eye Hospital, Puducherry
		52	Vinayaka Mission's Medical College, Karaikal, Puducherry UT
		53	JIPMER
	Tamil Nadu	54	Sankara Nethralaya Chennai
			Rela Institute chennai
		55	Aravind Eye Hospital, Madurai
		56	Aravind Eye Hospital, Coimbator
		57	Aravind Eye Hospital, Chennai
		58	Thoothukudi Medical College Hospital
		59	Dr Agarwal eye hospital
		60	CMC Vellore
	Telangana	61	Center for Sight Hyderabad
			Apollo Hyderabad
		62	LVPEI Hyderabad
			Apollo Hyderabad
West	Gujrat	63	Gujarat Cancer & Research Institute, Ahmedabad
		64	Shashwat hospital rajkot Gujarat
		65	Dhimahi Retina speciality hospital
		66	Oncovin
		67	SNEH Care Gujarat
		68	M & J Institute of Ophthalmology
	Chhattisgarh	69	MGM Eye Institute, Raipur
		70	AIIMS Raipur
		71	Balco Medical Centre
	Madhya Pradesh	72	Regional Cancer Center & Ratan Jyoti Eye Hospital, Gwalior
		73	Sadguru Netra Chikitsalaya, Chitrakoot
		74	State cancer institute,NSCB MC Jabalpur
		75	AIIMS Bhopal
		76	SAIMS
		77	Choithram Nethrayala
	Maharastra	78	TMH Mumbai
		79	Hinduja, Mumbai
		80	Narayana Health's SRCC Children's Hospital, Worli, Mumbai
		81	H.V. Desai Eye Hospital Pune
		82	Govt Cancer Hospital Aurangabad
		83	B.J. Wadia Hospital
		84	LTMG Sion Hospital
		85	Axis Eye Clinic
		86	Mahatma Gandhi Institute of Medical Sciences, Wardha
		87	Chintamani Eye And Dental Hospital
		88	MGM NEW BOMBAY HOSPITAL, VASHI
		89	AIIMS Nagpur
		90	Bharati Vidyapeeth

Annexure 2

Indian Journal of Ophthalmology Special Article



Annexure 2
Indian Journal of Ophthalmology Special Article

Guest Editorial

Fight retinoblastoma India: A decade of collective action, collaboration, and patient-centered care

Retinoblastoma (RB) can be cured with early detection, yet it remains a major challenge in low- and middle-income countries (LMICs). In India, with an estimated annual burden of approximately 1500–2000 children, outcomes have historically been affected by limited public awareness, delayed diagnoses, fragmented referral systems, lack of standardized protocols, and socioeconomic barriers that impede effective treatment. The absence of a unified national approach contributed to disparities in treatment options and unequal access to care.[1-4]

Over the past decade, RB care in India has undergone a significant transformation, with access to care now approaching near-universal levels. This progress reflects not only advances in clinical care but a deliberate shift toward a more patient-centered, collaborative approach that strengthens the entire continuum of care.

In 2013, the need for a unified national RB strategy led to the development of a multi-stakeholder platform—Fight RB India—convened by a national Civil Society Organization, CanKids KidsCan, in partnership with clinical leaders, institutions, and patient beneficiaries. Guided by the RB Vision 2020 framework and the one cancer at a time (OCAT) approach, the platform brought together ocular and pediatric oncologists, ophthalmologists, NGOs, community workers, donors, and survivors. Annual meetings enabled shared learning, alignment of strategies, and continuous strengthening of the network.

Over time, a nationwide network of RB treatment centers—now numbering 64—became aligned through this collaborative platform [Fig. 1]. These centers are distributed across regions of the country, including 17 in the North, 20 in the South, 15 in the West, and 12 in the East, extending access beyond major metropolitan areas into tier-2 cities and previously underserved geographies. Rather than creating new infrastructure, the initiative facilitated coordination and collaboration across existing institutions, enabling them to function as a more integrated system of care.

This regional spread has been critical in bringing treatment closer to home for many families, reducing travel burden, minimizing delays, and enabling earlier and more continuous access to appropriate care. A national referral directory further strengthened patient access to suitable centers. A key strength of this model has been its ability to align stakeholders across regions within a shared, patient-centered framework.

A key milestone has been the strengthening of standardized clinical care through collaborative effort. Research itself evolved as a collective endeavor, with clinicians and institutions coming together across the country to generate shared evidence. The first India Pediatric Oncology Group (InPOG)-led prospective multicenter study involving over 1000 patients played a critical role in building consensus on chemotherapy, focal therapy, brachytherapy, and enucleation.[5] The platform supported and enabled such collaborations by fostering trust, facilitating coordination, and creating an environment for multicenter research and data sharing. These efforts contributed to greater uniformity in care delivery and more consistent clinical decision-making across institutions.

Over the same period, advances in therapies and technology expanded the possibilities for RB care, including greater availability of focal therapies, brachytherapy, and globe-salvaging approaches such as intra-arterial and intravitreal chemotherapy. Within this collaborative framework, these advances were progressively adopted and disseminated across centers, enabling more children to benefit from contemporary, evidence-based care closer to where they live. This has had important implications not only for survival but also for eye salvage and long-term quality of life.

Public awareness became an essential element in early detection strategies. Nationwide campaigns promoted awareness of the "white reflex" through mass media and grassroots outreach, whereas frontline health workers such as Accredited social health activists (ASHAs) and Auxiliary nurse midwives (ANMs) were trained to recognize early symptoms and expedite referrals. Consistent support from philanthropic and Corporate social responsibility (CSR) partnerships enabled service delivery through patient assistance for diagnostics, drugs, advanced therapies, genetic testing, and counseling, along with dedicated social support teams, patient-centric, child-friendly Out patient department (OPDs), and wards, as well as research, capacity building, and stakeholder engagement. RB care was gradually incorporated into public insurance and welfare programs, helping to reduce out-of-pocket costs and improve treatment adherence.

Patient advocacy, psychosocial support, and survivorship were strengthened through the Jyotirgamaya ("from darkness to light") and other patient and survivor programs, which enabled survivors and their families to engage in awareness campaigns, policy discussions, and community initiatives. This survivor-led approach helped reduce stigma while improving adherence and psychosocial outcomes.

Over the last 10 years, this collaborative effort has achieved important milestones. Access to RB care has increased to near-universal levels, in contrast to approximately 54% access for pediatric cancers overall. Improved referral pathways and standardized care have contributed to reductions in treatment abandonment and delays, whereas financial and psychosocial support have reduced catastrophic expenditure and improved quality of life. Survivor advocacy efforts have boosted public awareness and informed policy dialogue, including efforts to integrate RB screening into national child health initiatives.

The achievement of near-universal access represents an important inflection point. With most children now entering the system, the focus can shift toward earlier detection, strengthening financial protection to cover advanced therapies, reducing rural–urban disparities, integrating RB care more fully into national health systems, improving survival outcomes, and ensuring continuity of care beyond treatment. Incorporating RB screening into programs such as the Rashtriya Bal Swasthya Karyakram, partnering with the Indian Academy of Paediatrics to include red reflex screening during routine immunization

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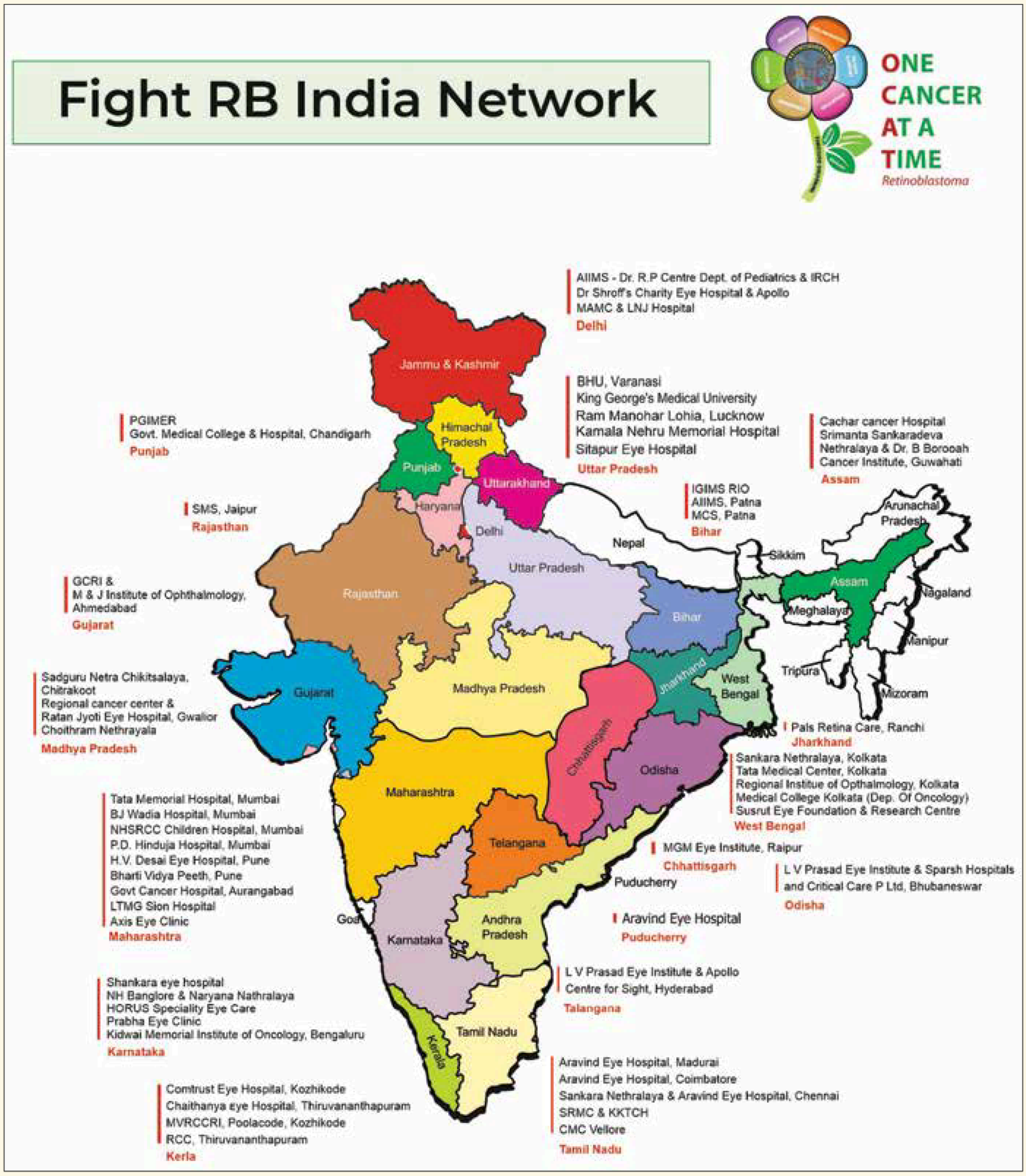

Figure 1: Map of India depicting the distribution of the 64 Fight Retinoblastoma (RB) India RB treatment centers

visits, and with AIOS for health information dissemination on RB care would further enhance early detection, particularly in underserved areas. Equally important is the expansion of rehabilitation and reintegration pathways—including visual rehabilitation, psychosocial care, and educational continuity—so that survivors not only live, but thrive. This experience demonstrates how collaborative, patient-centered approaches can transform pediatric oncology care in LMICs. Its progress has been driven by shared leadership, continuous learning, and the active participation of survivors and families.

Over the past decade, this collaborative effort has not only improved access and continuity of care but has also reshaped

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how care is delivered, how institutions collaborate, and how knowledge is collectively generated in real-world settings. As India moves toward broader goals of universal access, financial protection, and improved survival for childhood cancers, the lessons from RB offer a scalable framework for delivering comprehensive, equitable, and lifelong care.

Poonam Bagai, Santosh G. Honavar[1], Amita Mahajan[2], Sima Das[3], Haresh Gupta

Chairperson, CanKids KidsCan, New Delhi, [1]Ocular Oncology Service, Centre for Sight, Hyderabad, Telangana, [2]Department of Paediatric Oncology, Indraprastha Apollo Hospital, Delhi, [3]Ocular Oncology Service, Shroff Charity Eye Hospital, New Delhi, India
E-mail: poonambagai@cankidsindia.org

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Annexure 3

National Retinoblastoma Conclave 2026 Programme

Fight RB, India
RB India National Stakeholder Group

Cankidsindia.org

NATIONAL RETINOBLASTOMA CONCLAVE

FROM ACCESS TO SURVIVAL
INDIA IS FIGHTING RB AND WE ARE WINNING!

16TH MAY 2026

Constitution Club of India
Deputy Chairmen Hall,
2nd floor, New Delhi

ZOOM ID:
816 814 1045

AGENDA

Session 1
Welcome & Celebrating Life!
Atul Rathod, Retinoblastoma Survivor Ambassador
Preeti Phad, Retinoblastoma Survivor Ambassador

2:00-2:10 PM

Welcome Film
"RB Survivors Celebrate Life"

Opening Remarks & Setting the Tone

Invocation of Hope – Saraswati Vandana
Janki, RB Survivor

Session 2
The Journey So Far
India is Fighting RB and We Are Winning!
Preeti Rastogi, Parent Advocate & Survivor Parent
Dr Haresh Gupta, Deputy CEO, CanKids KidsCan

AGENDA

2:10-2:40 PM

From My Child To a National Movement
Preeti Rastogi, Parent Advocate & Survivor Parent

Framing the National Milestone
Dr Haresh Gupta, Deputy CEO, CanKids KidsCan

Interactive Poll
What Changed Outcomes in India?

Fight RB India
From Challenge to National Movement
Poonam Bagai, Founder Chairman, CanKids KidsCan

Session 3
Partners & Collaboration
Science, Systems & Shared Care
Preeti Phad, Retinoblastoma Survivor Ambassador
Dr Manas Kalra, Senior Consultant, Paediatric Haematology Oncology & BMT, Sir Ganga Ram Hospital

2:40-3:15 PM

The Survivor Voice For The Systems Change
Preeti Phad, RB Survivor

IAP & Pediatrics: Making RB Screening Everybody's Business
Dr Neelam Mohan, President, Indian Academy of Pediatrics

AIOS & Ocular Oncology: Building India's Early Detection & Treatment Network
Dr Bhawna Chawla, Professor of Ophthalmology, AIIMS Delhi
Dr Jeewan Singh Titiyal, President, AIOS (Video Message)

INPHOG & Collaborative Research: Registries & Lessons from India
Dr Amita Mahajan, Senior Consultant, Apollo and lead Project Suddridh
Dr Ramandeep Arora, Director, INPHOG (Video)

Donor Reflection
Ms Kanaka Sirpal, RB Donor

AGENDA

Session 4
The National Ask
From Access to Financial Protection & Survival
Poonam Bagai, Founder Chairman, CanKids KidsCan
Vikash Yadav, RB Survivor

3:15-4:00 PM

The Human Face Of Policy Change!
Vikash Yadav, RB Survivor

Mr. Prime Minister - Do You See What Eye See ?
Film + PMO Message

Ayushman Bharat & Financial Protection for Children with Retinoblastoma
Dr Pankaj Arora, Director, NHA, Government of India

Chief Guest Recorded Address: India's Opportunity to Lead in Patient-Centred Childhood Cancer Care
Dr M. Srinivas, Member, NITI Aayog

SPECIAL MOMENT
Documenting India's Journey

Launch & Recognition of IJO Publication
Authors, Stakeholders & Dignitaries

Session 5
2030 Goals – The Way Forward
Saving Lives, Saving Vision, Saving Childhood
Shivam Dubey, RB Survivor
Dr Nishant Verma, Professor, Department of Pediatrics KGMU, Lucknow

Fight RB, India
RB India National Stakeholder Group

Cankidsindia.org

AGENDA

4:00-4:45 PM

Young Survivor Voice
"The Future We Want"
Shivam Dubey, RB Survivor

Vision 2030: Towards 80–90% Survival & Vision Preservation
Dr Santosh Honavar, Director, Centre for Sight, Hyderabad

National Call to Action: What Must India Do Next? Group Recommendations
Dr. Amita Mahajan & Dr. Neelima Thakur

Honouring the Movement: Survivors, Stakeholders & Champions
Key Stakeholders & Survivors

4:45-5:00 PM

Media Interaction & Closing Conversations
Media & Key Speakers

Together let's do
CANCER
KO
DHISHOOM DHISHOOM
GIFT EVERY CHILD A GOLDEN TOMORROW

Annexure 4
Media Coverage

National Retinoblastoma Conclave

"From Access to Survival – India is Fighting Retinoblastoma"

SAVE LIVES
SAVE EYES
SAVE VISION

Media & Advocacy Impact Report

The National Retinoblastoma Conclave received strong national visibility across print, digital, healthcare, regional, Hindi, English, radio, and advocacy platforms. The outreach highlighted India's growing progress toward near-universal access to Retinoblastoma care, survivor-led advocacy, early detection, affordability concerns, and the importance of collaborative healthcare systems.

The conclave successfully brought together clinicians, survivors, researchers, policymakers, hospitals, caregivers, and civil society organizations to strengthen the future of childhood eye cancer care in India.

1 Key Coverage Highlights

Policy & National Healthcare Recognition

Several leading media platforms prominently highlighted the statement of M. Srinivas, appreciating India's Retinoblastoma care model as an example for global healthcare systems.

Major Headlines

- "Near-universal access to eye cancer care in India a model to emulate"
- "India achieves near universal access to retinoblastoma care"
- "भारत में नेत्र कैंसर के इलाज की सार्वभौमिक पहुंच एक अनुकरणीय मॉडल है"

Platforms Covered

- The Hans India
- Punjab Kesari English
- Punjab Kesari Hindi
- Lokmat Times
- TenNews
- NewKerala
- Social News XYZ
- Morung Express

2 Print Newspaper Coverage

The campaign also received important newspaper visibility highlighting the urgency of early detection and timely treatment in Retinoblastoma care.

Featured Print Coverage


Retinoblastoma's early detection, timely treatment critical to saving life, vision, childhood

Published in:

- The Statesman

The article highlighted:

- importance of early diagnosis,
- multidisciplinary treatment systems,
- collaborative healthcare networks,
- and India's expanding Retinoblastoma care ecosystem.

It also emphasized how coordinated stakeholder efforts are improving access, continuity of care, and survival outcomes for children across India.

3 Survivor Advocacy & Human Impact Stories

A strong emotional angle emerged through stories focusing on survivors giving hope to children battling eye cancer.

Human-Centric Headlines

- "Eye cancer survivors giving new hope to children across the country"
- "No child should lose sight due to high treatment costs"

These stories successfully positioned survivor voices and patient advocacy at the center of the campaign.

Platforms Covered

- LaatSaab
- Drug Today Online

The coverage prominently featured Poonam Bagai and highlighted the need for affordable, accessible, and equitable care for every child in India.

4 Hindi Media Reach

Hindi media gave extensive visibility to the campaign, helping the message reach families and communities beyond metro cities.

Hindi Headline Impact

- "भारत में नेत्र कैंसर के इलाज की सार्वभौमिक पहुंच"
- "आखों के कैंसर से जंग में भारत की बड़ी उपलब्धि"

Major Hindi Platforms

- Bhaskar Hindi
- Punjab Kesari Hindi
- LaatSaab Hindi Coverage

This regional-language amplification strengthened awareness among grassroots communities, caregivers, and parents.

5 Radio, Live Interviews & Digital Amplification

The advocacy campaign expanded beyond print and digital news into broadcast and live media conversations.

Broadcast Outreach Included

- Half-hour special coverage on ALL India Radio
- Phonic Live Interview
- Social media amplification through digital platforms and advocacy pages

Social Media Mention

- YesPunjab on X (Twitter)

This helped amplify the conclave messaging to wider public audiences and increased awareness around childhood eye cancer nationally.

6 Advocacy Through Storytelling & Survivor Leadership

The conclave demonstrated how survivor-led advocacy, collaborative healthcare communication, and emotional storytelling can create national impact.

The campaign positioned childhood eye cancer not only as a medical issue, but also as:

- a healthcare access issue,
- a survivorship issue,
- and a human rights issue.

The advocacy messaging strongly reflected the collective mission:

SAVE LIVES | SAVE EYES | SAVE VISION

Articles links:

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5. https://thedailyvoice.in/indias-major-triumph-against-retinoblastoma-treatment-reaches-across-the-nation/
6. https://healthonair.in/latest-in-health/india-nears-universal-retinoblastoma-care-targets-higher-survival/
7. https://www.punjabkesari.com/india-news/bharat-mein-netra-cancer-ke-ilaj-ki-sarvabhaumik-pahunch-ek-anukarniya-model-hai-m-srinivas/
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13. https://newkerala.com/news/often-overlooked-retinoblastoma-prof-srinivas-calls-for-awareness-and-early-action/
14. https://socialnews.xyz/india-achieves-near-universal-access-to-retinoblastoma-care-says-niti-aayog/
15. https://www.morungexpress.com/india-achieves-near-universal-access-to-retinoblastoma-care
16. https://laatsaab.com/hindi/bharat-mein-netra-cancer-ke-ilaj-ki-sarvabhaumik-pahunch-ek-anukarniya-model-hai-m-srinivas/
17. https://phonic.fm/radio/podcast/episode/india-nears-universal-retinoblastoma-care-a-step-towards-better-childhood-eye-health/
18. https://x.com/yespunjab/status/1913129456789125188



THE FIRST DECADE WAS ABOUT ACCESS

THE NEXT DECADE MUST BE ABOUT SURVIVAL.

SAVE LIVES – SAVE EYES – SAVE VISION

THE PATIENT MUST ALWAYS REMAIN AT THE CENTRE.

Dedicated to every child, family, survivor, clinician,
researcher, advocate, volunteer and partner
who chose to fight **Retinoblastoma** together.

ONE CANCER AT A TIME
Retinoblastoma

Fight RB, India
RB India National Stakeholder Group

INDIAN ACADEMY OF PEDIATRICS

FROM DARKNESS TO LIGHT

Pediatric Hematology and Oncology Chapter
Indian Academy of Pediatrics

CANKIDS KIDSCAN
National Society for Change for Childhood Cancer in India