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Impact of healthcare strategies on patterns of Paediatric Sight Impairment in a developed population: 1984-2011

Key Words:

Paediatric visual impairment, Public health, Childhood vision

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Conflict of interest:

The authors declare no conflict of interest.

Abstract

Purpose:

The aim of our study was to analyse paediatric sight-impairment trends in Northern Ireland (NI) over a 28-year period to better understand the impact which changes in healthcare provision may be having on childhood blindness and to enable us to assess our progress towards achieving the World Health Organisations (WHO) aims.

Methods:

A database of Certificates of Visual Impairment completed for NI children under 16 years old was used to determine cause of sight-impairment from 1984 to 2011. Causes were classified into preventable or treatable conditions and analysed for trends.

Results:

598 children were registered as having impaired vision over the 28-year period. 22% had preventable or treatable conditions. Optic atrophy was the most common cause responsible for 16% of registrations followed by albinism (12%), cerebral visual impairment (CVI) (11%), congenital cataract (8%), retinopathy of prematurity (ROP) (8%) and congenital motor nystagmus (CMN) (7%).The incident rate (per million population under 16 years of age) for registerable vision loss due to congenital cataract decreased from 5.89 (CI 2.82-10.83) in 1984-1987 to 2.63 (CI 0.72-6.74) in 2008-2011. For retinopathy of prematurity, the incident rate peaked during 2000-2003 at 8.87 (CI 4.85-14.88). Thereafter, there was a statistically significant reduction in incident rate to 1.98 (CI 0.41-5.77) in 2008-2011 (p=0.008).

Conclusions:

Sight-impairment registrations due to preventable or treatable causes have decreased over the last 28 years. This is likely due to better surgical techniques and improved refractive care for conditions

such as congenital cataract and ongoing research and treatment protocols for conditions such as ROP. Future advances in this area may help to further reduce the burden of childhood sight-impairment and improve quality of life for these patients.

Main Article

Introduction

Preventable sight-impairment has been a major focus of the World Health Organisation (WHO) for many years. In 1999, WHO published its initiative for eliminating avoidable blindness, VISION 2020-The Right to Sight (1). Its vision is a world in which no one is needlessly blind and those with unavoidable vision loss can achieve their full potential (1). Childhood blindness is one of the priority eye diseases highlighted in this document. An estimated worldwide prevalence of 1.4 million blind children confers significant social, economic and emotional impact on society (2). Major focus is on the preventable or treatable causes which are felt to account for 40% of childhood blindness (3). The main avoidable causes of visual impairment worldwide are corneal scarring, cataract, glaucoma, retinopathy of prematurity (ROP) and refractive errors (3). Early treatment of these conditions is vital to prevent amblyopia and ensure normal visual development (4).

Worldwide, there have been several breakthroughs since the publication of VISION 2020 in relation to childhood blindness. The United Nations Children's Fund (UNICEF) estimates significant reduction in Vitamin A deficiency-related visual impairment due to the implementation of the Vitamin A global Initiative (3). The Measles initiative has reduced measles related deaths by 28% from 1999 to 2004 and an associated reduction in the incidence of corneal scarring is expected (3).

WHO outlined objectives for 2020 in relation to childhood blindness which include provision of services to treat children with cataract, glaucoma, ROP and corneal scarring (3). It also states that optical services to address refractive errors and provision of low vision services should be made available.

The aim of our study was to analyse paediatric sight-impairment trends in Northern Ireland (NI) over a 28-year period to give us a better understanding of the impact which changes in healthcare provision may have had on childhood sight loss and to enable us to assess our progress towards achieving the WHO aims for VISION 2020.

Methods

A database with information gathered from Certificates of Visual Impairment completed for NI residents from 1984 is held by the hospital optometric department of the Belfast Health and Social Care Trust (BHSCT). The Certificate of Visual Impairment form for Northern Ireland is available for viewing on the Royal College of Ophthalmologists website. (5)

As the data available after 2011 was incomplete, due to issues with lack of staff to maintain the database, data was extracted for all patients under 16 years of age who were registered as either sight-impaired (SI) or severely sight-impaired (SSI) between 1984 and 2011 inclusive. This information was then entered into and analysed using Microsoft Excel 2007. Of note, data was not available for 1989 or 1998; again, due to staffing issues impacting on database maintenance.
Full approval was obtained from the Belfast Health and Social Care Trust Standards, Quality and Audit department and data was managed in accordance with BHSCT current guidance on data protection.

We adhered to the definitions for sight-impaired and severely sight-impaired as set out by the Department of Health, Certificate of Visual Impairment: Explanatory notes for Consultant Ophthalmologists and Hospital Eye Clinic Staff issued in September 2007. (6). This document defines severe sight-impairment as Snellen visual acuity less than 3/60, or visual acuity between 3/60 and 6/60 with a very contracted field of vision, or visual acuity above 6/60 but contracted field of vision especially inferiorly. In our paediatric population, equivalent visual acuity measurements using other optotypes were valid, or if visual acuity could not be measured formally, clinical features of visual

104 defects (eg. not fixing or following to light) were included but classified as sight-impaired. The 2007
105 Department of Health document defines sight-impairment as Snellen visual acuity between 3/60 and
106 6/60 with full field, visual acuity up to 6/24 with moderate field contraction, opacities in the media
107 or aphakia, or visual acuity of 6/18 or better with marked field contraction (6). We appreciate that
108 these definitions do not directly correlate with the WHO 2016 ICD-10 definitions of mild, moderate
109 and severe visual impairment and blindness (7).

110 However, as we analysed data from Certificates of Visual Impairment, we felt it was appropriate to
111 present this data using the Department of Health Certificate of Visual Impairment definitions of
112 sight-impairment and severe sight-impairment.

113 Based on the information on the cause of reduced vision in each patient, we classified aetiology
114 using a dual taxonomy described by Rahi et al (8). The causes were classified in two ways: by
115 individual disorders, grouped by the anatomical site affected, and by timing of specific causal factors
116 leading to vision loss.

We further classified the individual disorders causing sight loss into preventable or non-preventable and treatable or non-treatable based on current understanding with a view to identifying the proportion of avoidable vision loss in our study population.

Looking at the sight-impaired and severe sight-impaired registrations as a whole, the six leading causes of reduced vision were identified for our NI population. For every 4-year period between 1984 and 2011, we identified the number of registrations for each condition and estimated the annual incident rates per million population under 16 years of age. In the periods which included one year of missing data (1988-1991 and 1996-1999), incident rates were computed using the available information (3 years in each case). 95% confidence intervals were computed for the incidence rates assuming a Poisson distribution model. In comparisons between periods, statistical significance of differences in incidence rates was assessed using Fisher's exact test. Poisson regression model analysis was used to check for trends in incidence rates over the seven 4-year periods. Differences and trends in incidence rates with a p value of less than 0.05 were considered statistically significant. Analysis was performed using MATLAB® 9.1 (R2016b).

Results

Five hundred and ninety-eight children were registered as having impaired vision over the 28-year period (Figure 1). Two hundred and thirty-four (39%) were registered as sight-impaired and three hundred and sixty-four (61%) were registered as severely sight-impaired. 53% were males and 26% had associated systemic conditions (table 1). The mean age at registration was 7.4 years (SD± 4.6 years) with a range of 2 months to 16 years. Three of these patients had no cause of sight-impairment documented on their registration forms and were therefore excluded from further analysis.

The timing of the insult was prenatal in 69% (of which 77% were hereditary/congenital), perinatal/neonatal in 22%, and occurred during childhood in 9% (Table 2). Three hundred and fifty-

seven cases (60%) were neither preventable nor treatable. Of the remaining 238 cases, 132 (22%) were considered either preventable or treatable and 104 (18%) were considered to be possibly preventable or treatable (Table 3).

Anatomically, the majority (37%) of registrations for impaired vision were due to retinal disorders. Only 31% of these 218 patients with retinal pathology had potentially preventable/treatable causes such as ROP or Autosomal Dominant Retinal Dystrophy.

Overall the most common cause of vision loss was optic atrophy (16%); of these 39% were primary optic atrophy and 61% had secondary optic atrophy. The subsequent five main causes in order after optic atrophy were, albinism (12%), cerebral visual impairment (CVI) (11%), congenital cataract (8%), retinopathy of prematurity (ROP) (8%) and congenital motor nystagmus (CMN) (7%).

When we analyse the incident rates for the six leading causes of all registrations (sight-impaired and severe sight-impaired) in Northern Ireland for each 4-year period from 1984-2011, we can identify some interesting trends in both the preventable/treatable conditions and also the non-preventable/non-treatable conditions (Figure 2).

Incident rates for optic atrophy and albinism fluctuate over the years but there was no significant change between 1984-1987 and 2008-2011 for either condition (p for trend = 0.88 and 0.94, respectively). This reflects the fact that visual loss due to either optic atrophy or albinism can neither be prevented nor treated.

Cerebral visual impairment as a cause for registration shows a general upward trend over the last 28 years. The incident rate increased from 1.77 per million (CI 0.36-5.16) in 1984-1987 to 12.51 per million (CI 7.53-19.54) in 2008-2011. This 7-fold increase was statistically significant (p for trend <0.0001).

Congenital motor nystagmus also shows a significant upward trend with an incident rate of 0.59 per million (CI 0.01-3.28) in 1984-1987 increasing to 8.87 per million (CI 4.85-14.88) in 2000-2003 (p for

difference =0.0003); at which point, it dramatically reduces to 0.66 per million (CI 0.02-3.67) in 2008-2011 (p for difference=0.0006).

The two main preventable/treatable causes of paediatric vision loss which show interesting trends over the last 28 years are congenital cataract and retinopathy of prematurity which together are responsible for 16% of reported sight-impairment and severe sight-impairment.

The incident rate for congenital cataract decreased from 5.89 per million (CI 2.82-10.83) in 1984-1987 to 2.63 per million (CI 0.72-6.74) in 2008-2011. This 2-fold decrease in registered vision loss due to congenital cataract failed to reach statistical significance (p for trend =0.053).

The incident rate for retinopathy of prematurity reduced from 5.30 per million (CI 2.42-10.06) in 1984-1987 to 0.80 per million (CI 0.02-4.45) in 1988-1991 (p for difference=0.03) but peaked again during 2000-2003 with an incident rate of 8.87 per million (CI 4.85-14.88). Thereafter, there was a statistically significant reduction in incident rate to 1.98 per million (CI 0.41-5.77) in 2008-2011 (p for difference=0.008).

Discussion

The Northern Ireland (NI) Statistics and Research Agency reported a paediatric population (< 16-year-old) of 379 323 following the 2011 NI Census (9). We identified 21 new cases of children registered with impaired sight in 2011; giving an annual incidence of 0.55 per 10 000 (CI 0.34-0.84). Of these 21 children, 13 were registered as severely sight-impaired giving an incidence of blind registrations of 0.34 per 10 000 (CI 0.18-0.58) in 2011 in children under 16 years of age which is comparable to Mitry et al's reported annual incidence of new blind registrations of 0.41 per 10 000 in 2011 in children under 17 years of age in a similar study conducted in England (10).

A 1976 Northern Ireland population study by Bryars and Archer, identified genetic disease and birth hypoxia as the leading causes of significant sight-impairment (11). This finding has been replicated in

189 the current study with 56% of severely sight-impaired children having perinatal hypoxia or
190 hereditary/congenital causal factors recorded on their registration forms.

191 Avoidable causes of blindness have been given priority by the WHO organisation and retinopathy of
192 prematurity is recognised as one of those conditions. ROP contributed to 8% of all registrations in
193 our overall study population but there were significant fluctuations over time. Our study data
194 extends back to 1984 and the first significant change in incident rate for vision loss secondary to ROP
195 occurred between 1984-1987 and 1988-1991 when there was a 6.6-fold reduction in incident rate
196 (CI 0.92-291.06, p for difference=0.03). This decline coincided with the publication of the results of
197 the CRYO-ROP trial in early 1988. This large multicentre trial demonstrated that those neonates with
198 threshold ROP treated with cryotherapy had a significantly lower rate of adverse outcome compared
199 to those untreated (21.8% vs 43%) (12). This study clearly impacted on the visual outcome of
200 neonates with ROP as demonstrated by our findings. As the percentage of preterm babies surviving
201 annually continued to increase and the survival rate for those born at extremely low gestational age
202 (less than 26 weeks) continued to improve with advancing neonatal care, the rate of sight-
203 impairment attributable to ROP in NI steadily increased after 1988-1991 (13) (14). With the hope of
204 further lowering the rate of adverse outcomes, the National Eye Institute put together a
205 collaborative group to study earlier treatment for ROP (ETROP), the results of which were published
206 in 2003 (15). The ETROP study was pivotal in highlighting the importance of early ablative therapy in
207 improving visual outcomes for patients with high risk ROP. Our study demonstrates coinciding
208 positive effects on childhood vision with the incident rate for vision loss due to ROP falling from its
209 highest level of 8.87 per million during 2000-2003 to 1.98 per million in 2008-2011**.** The adoption of
210 the ETROP recommendations for earlier treatment of ROP was also reflected in the reported
211 increase in ROP treatments in Northern Ireland with the percentage of 'at risk' infants surviving to 42
212 weeks gestational age requiring ROP treatment increasing from 1% in 2000 to 5.8 % in 2011 (14).

The most common treatable cause of vision loss in our population was cataract (8% of all registrations) which also demonstrated an interesting trend with incident rates decreasing by 50% over the 28-year period. At the start of our study, congenital cataracts were responsible for 14% of the 72 registrations during 1984-7 which gradually declined to 5% of the 84 registrations during 2008-11 (Figure 2). This is comparable to the findings of a large study performed by the British Childhood Visual Impairment Study Group (BCVISG) which also reported 5% of severe visual impairment to be caused by cataract in 2000 (8).

Although the incidence of congenital cataract is relatively low in developed countries such as the United Kingdom (UK), it remains the leading cause of surgically correctable blindness worldwide (16). In the UK, during the 1960s and 1970s, UK child health surveillance programmes began to develop which recognised the importance of vision screening in children. By the late 1980s, these programmes were being rationalised and more robust screening programmes for pre-school children were established (17). Newborn screening should now occur within the first 72 hours after birth and between 6 and 8 weeks of age to identify any abnormality of the red reflex (18). This early detection of cataract is vital in providing timely treatment for what is an extremely amblyogenic condition. Although it did not reach statistical significance, the observed downward trend in vision loss due to cataract may possibly be explained by this early detection in addition to improved surgical techniques and refractive aftercare (16).

Cerebral visual impairment (CVI) as a cause for registerable visual loss demonstrated a 7-fold increase in incident rate between 1984-1987 and 2008-2011. This is now one of the main causes of impaired vision in our population and although it is not treatable or reversible it should be a focus of study and investment to reduce the impact on patient quality of life. This increase in CVI may be explained by the improvement in neonatal care for the premature or disabled child, resulting in increased survival rates. The proportion of premature neonates has not significantly increased over the last 28 years (19). However, the survival rate of these preterm infants has greatly improved due

to the improved neonatal care. In the UK and Wales, neonatal mortality rate fell by 60% from 7.7 deaths per 1000 live births in 1980 to 3.1 deaths per 1000 live births in 2009 (20). This along with increased awareness and reporting are possible explanations for the significant increase in reported cases of CVI.

Another interesting trend which may reflect the effect of improved diagnostic investigations is the observed changes in incident rates in congenital motor nystagmus and albinism over the last decade. In 2004-2007, the incident rate for registration due to congenital motor nystagmus was 7.26 per million (CI 3.63-13.00) which decreased to 0.66 per million (CI 0.02-3.67) in 2008-2011 (p for difference =0.003). This decrease coincided with an increase in the incident rate for registrations due to albinism from 3.96 per million (CI 1.45-8.62) in 2004-2007 to 7.24 per million (CI 3.62-12.96) in 2008-2011 (p for difference=0.17).

Foveal hypoplasia has long been recognised as an associated feature of albinism, even in mild cases, but is not evident in patients with congenital motor nystagmus (21). With improved availability of optical coherence tomography, foveal hypoplasia is now a much more easily identified feature. In turn, children who were once diagnosed as having congenital motor nystagmus may be now more correctly diagnosed as having ocular albinism.

Our patient cohort is population-based. According to migration statistics, immigration in NI is greater than emigration making Northern Ireland an ideal population for epidemiological studies. Our study, like other published studies on paediatric sight-impairment, analysed data from registration databases which are largely non-compulsory and therefore may not have captured all children with significant sight-impairment. A further limitation of our study, was the lack of data collection for 1989 and 1998 due to staffing issues. We also recognise that the concept of childhood sight-impairment has changed over the last 3 decades and 'blind' registers do not comprehensively capture all children with complex visual needs (22).

The data is useful, however, as a minimum estimate and can provide useful indication of trends. This study demonstrates the positive impact improvements in healthcare and disease prevention can have on the quality of life of our paediatric population. In line with the aims of VISION 2020, the implementation of effective screening and treatment protocols for preventable and treatable conditions has resulted in a decreasing trend in some of our leading causes of paediatric sight-impairment. Future advances in therapies for genetic ophthalmic disorders may help to further reduce the burden of childhood sight-impairment due to currently non-treatable and non-preventable conditions such as albinism and hereditary optic atrophy.

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Conflict of interest:

The authors declare no conflict of interest.

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Titles and Legends to figures

Table 1: Demographic details, associations and timing of insult for severely sight-impaired and sight-impaired children.

Table 2: Causal factors categorised into time of insult.

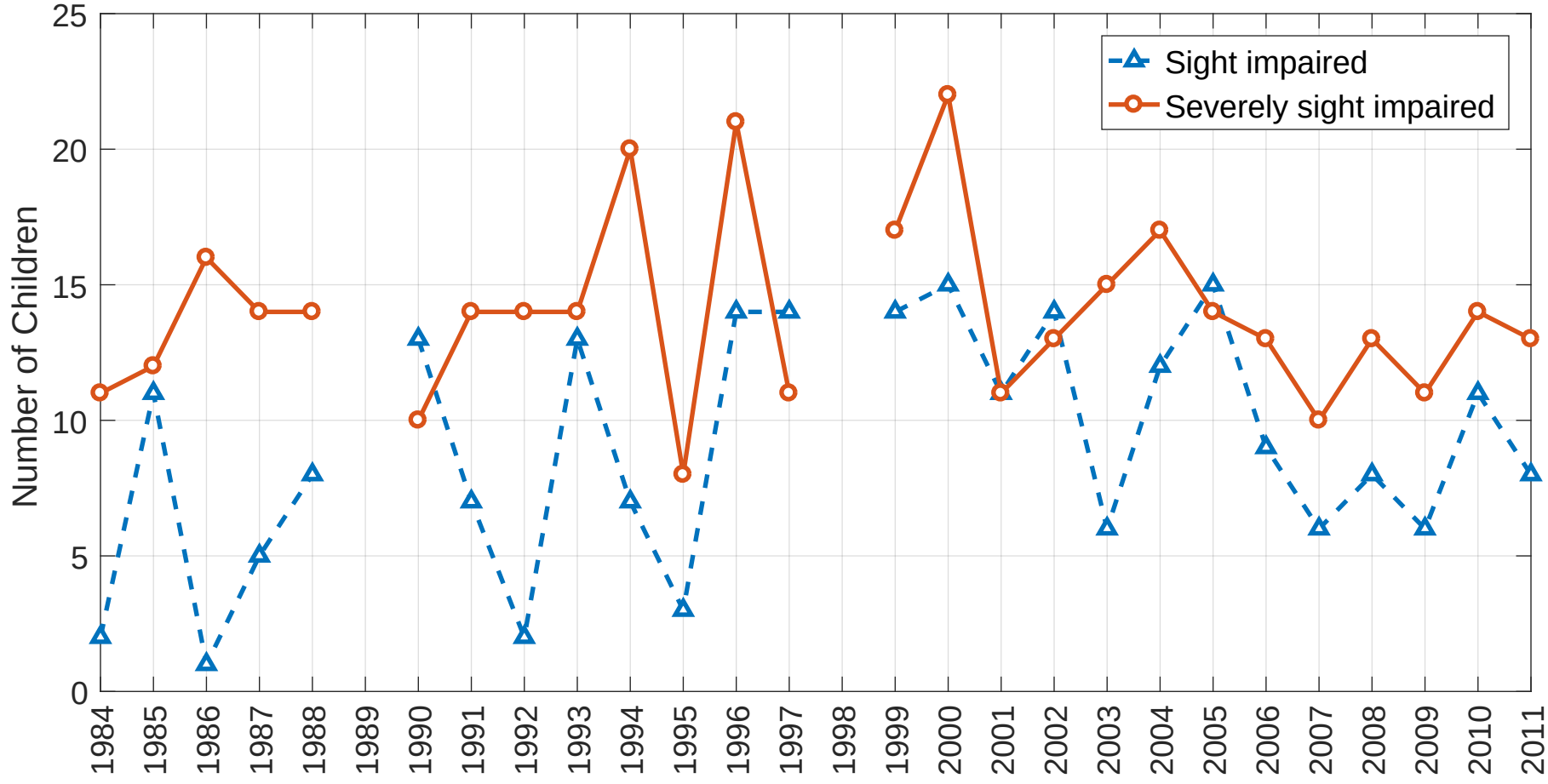
Table 3: Potentially preventable or treatable causes.

Figure 1: The number of children registered as severely sight-impaired and sight-impaired per year. (Note: Data not collected for 1989 and 1998)

Figure 2: Incident rates (per million population under 16 years of age) for the six leading causes of paediatric sight impairment in Northern Ireland for each 4-year period from 1984 to 2011. (ROP=Retinopathy of Prematurity, CVI=Cerebral Visual Impairment).

Supplemental Table:

Table 4: Cause of vision loss by anatomical location


Sight impaired
Severely sight impaired
Number of Children
0
5
10
15
20
25
1984
1985
1986
1987
1988
1989
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1991
1992
1993
1994
1995
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1997
1998
1999
2000
2001
2002
2003
2004
2005
2006
2007
2008
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2011

Table 1: Demographic details, associations and timing of insult for severely sight-impaired and sight-impaired children.

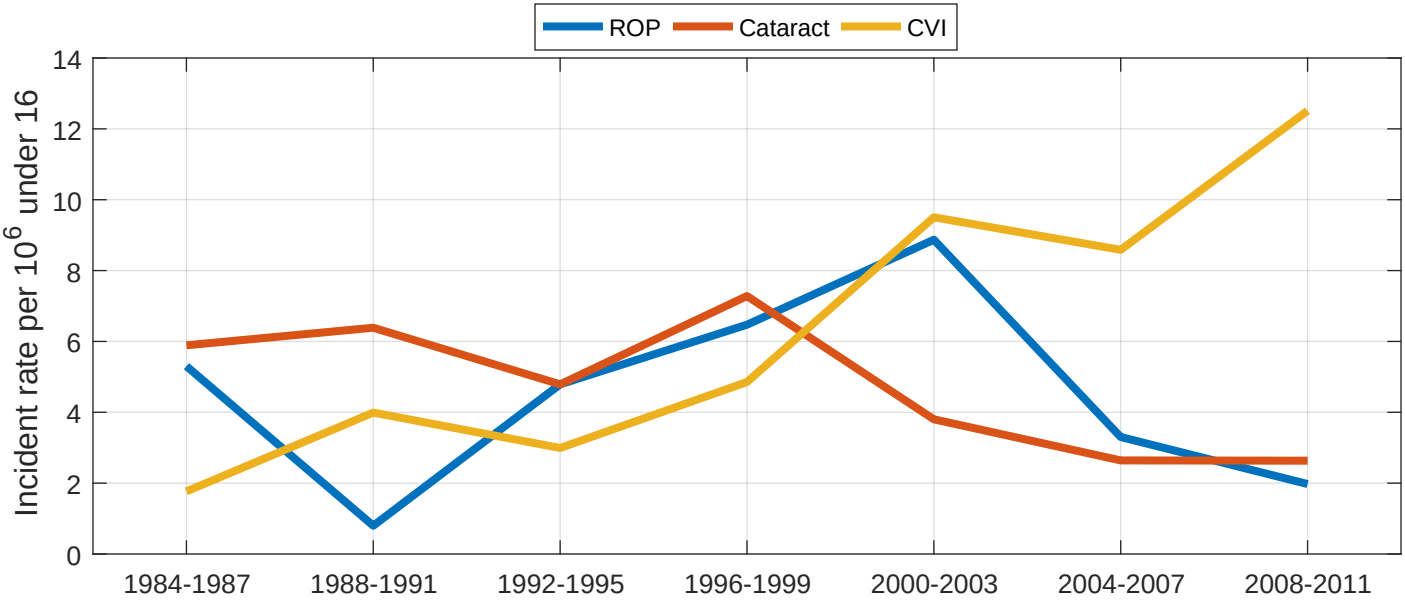
	Severely sight impaired *(n=364)*	Sight impaired *(n=234)*	Overall *(n=598)*
Gender			
Male	181	134	315
Female	181	98	279
Unknown	2	2	4
Age			
<1	20	1	21
1-4	121	48	169
5-15	212	176	388
Unknown	11	9	20
Positive Family History of condition	39 (11%)	32 (14%)	71 (12%)
Known associated Systemic/syndromic condition	125 (34%)	28 (12%)	153 (26%)
Time of insult			
Prenatal	222 (61%)	187 (80%)	409 (68%)
Perinatal/Neonatal	110 (30%)	19 (8%)	129 (21%)
Childhood	30 (8%)	27 (11%)	57 (10%)
Unknown	2 (1%)	1 (1%)	3 (1%)

Table 2: Causal factors categorised into time of insult.

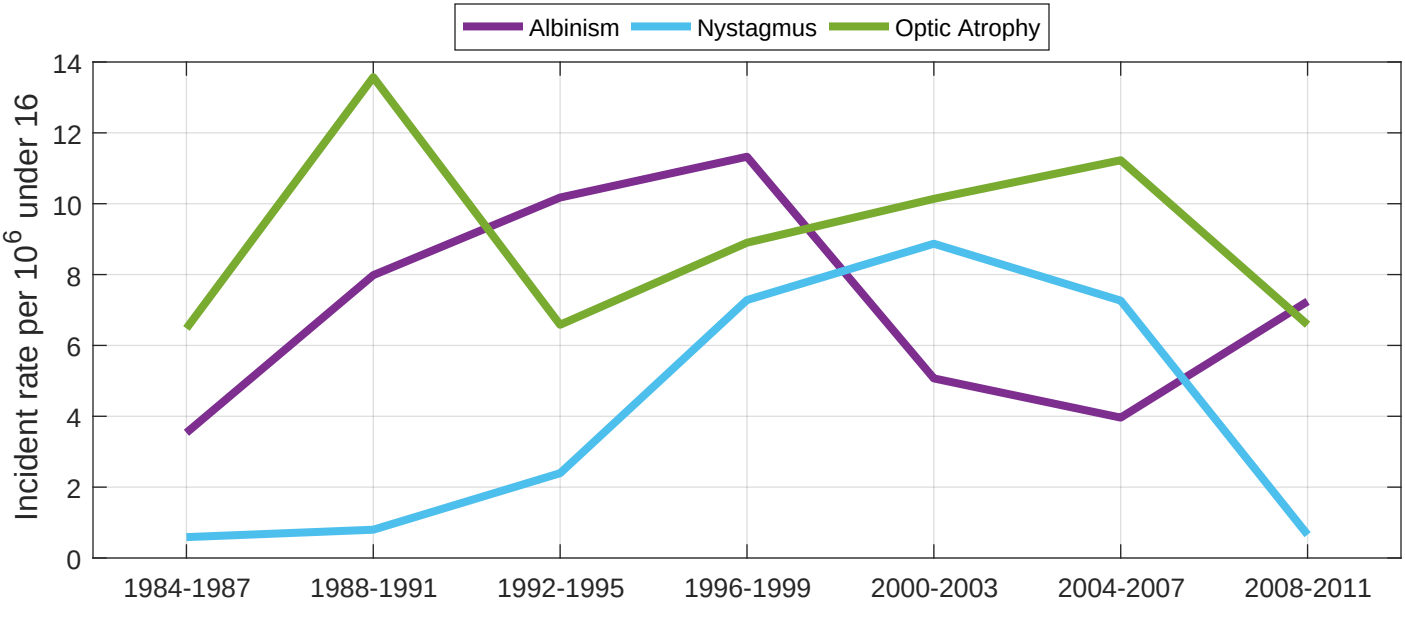
	Severely sight impaired *(n=362)*	Sight impaired *(n=233)*	Overall *(n=595)*
Prenatal	*n=222*	*n=187*	
Hereditary/congenital	153	163	316
Infection	4	2	6
Other	65	22	87
Perinatal/Neonatal	*n=110*	*n=19*	
Hypoxia/Ischemia	50	3	53
Infection	2	0	2
Hydrocephalus	10	5	15
Other	48	11	59
Childhood	*n=30*	*n=27*	
Tumour	12	5	17
Infection	2	0	2
Refractive	4	12	16
Accidental injury	1	1	2
Systemic disorders	6	4	10
Other	5	5	10

Table 3: Potentially preventable or treatable causes.

	Number of children *(n=595)*
Preventable	*Total=50 (8%)*
Retinopathy of prematurity	48
Prenatal Rubella	2 (cataracts)
Possibly Preventable	*Total=44 (7%)*
Autosomal Dominant Conditions	
-Aniridia	2
-Retinal dystrophy	11
-Primary optic atrophy	9
-Congenital glaucoma	2
-Congenital Cataract	11
-Retinoblastoma	2
-Other	5
Trauma	2
Treatable	*Total= 82 (14%)*
Refractive error	17
Uveitis	3
Glaucoma	15
Ectopia lentis	7
Cataract	32
Retinal detachment	2
Retinoblastoma	4
Meningitis	1
Infection	1
Possibly treatable	*Total=62 (10%)*
Hydrocephalus	21
Tumour	18
Toxoplasmosis	5
Other	18
Not treatable or preventable	*Total= 357 (60%)*



(a) ROP, Cataract & CVI



(b) Albinism, Congenital Nystagmus & Optic Atrophy