

EYES

Recommended Specialists - Pediatric Ophthalmologist and/or Retinal Disease Specialist, Ophthalmologist

The IP eye exam is imperative to be completed as soon as possible once IP is known at birth or thereafter.

REQUIRED EYE EXAMINATIONS FOR THOSE AFFECTED WITH IP

A dilated fundus exam as soon after birth as the Neonatologist or Anesthesiologist thinks it is safe. Sometimes, if there are any suspected retinal abnormalities, an examination under anesthesia is required. The important thing is for the ophthalmologist to look at the optic nerve head, the macula (in the center of the retina), and the far peripheral retina where, the typical pathologic events tend to occur.

This should be done before the babies leave the hospital.

UNLESS there is a known allergy to fluorescein in the family or in the patient, a fluorescein angiogram is highly recommended, regardless of age, initially and at follow-up, and unless the retinal specialist decides the view of the retina is easily and completely obtainable without the angiogram. Frequency of repeat angiograms is based on the retinal specialist's interpretation of the retinal findings obtained with routine examination techniques.

Severe retinal disease is often associated with brain dysfunction and is a marker to pursue x-ray scanning studies of the head. With respect to the eyes themselves, some babies with IP, and even some older patients, might benefit from laser treatment in an effort to prevent retinal detachment or vitreous hemorrhage from the consequences of the typical retinal neovascularization that occurs in this disorder.

If eyes are okay upon the initial full IP eye exam and there after - eye appointments with dilation follow-ups should be scheduled monthly until age four months, then every three months from age four months to one year, every six months from age one to three years, and annually after age three years for life.

If an issue or question should arise at anytime during an exam immediately see a retinal specialist and refer back to the full IP Eye Exam

If any head trauma occurs at any time throughout like an eye exam is highly suggested as soon as possible for both partial and full retina detachment.

The majority of IP patients have normal vision. Some problems, like near - and far - sightedness, are common in IP, but these are probably no more frequent than in the general population without IP. The classical eye finding in IP is an abnormality in the growth of blood vessels in the inside of the eye (the retina). Growth of abnormal blood vessels and the associated scarring can cause loss of vision but may be treated if recognized early enough. For this reason, babies diagnosed with IP should have the full IP eye examination immediately after birth and be followed by an ophthalmologist closely. Careful examination by a pediatric ophthalmologist or retinal disease specialist should be done

Rare eye abnormalities have included small eye (microphthalmos), cataract, and degeneration of the optic nerve (optic atrophy). Permanent visual deficiency or total blindness may occur.

IP Eye Exams are Medical Not Routine for insurance purposes.

Morton F. Goldberg, M.D.

Director and William Holland Wilmer
Professor of Ophthalmology
The Wilmer Ophthalmological Institute
Johns Hopkins University School of Medicine
Tel: 410 955-6846
Fax: 410 955-0675
Email: goldbrg@jhmi.edu

Dr. Goldberg would like to offer his services to any patients who might benefit from ophthalmic consultation and/or treatment under his personal direction. He is the author of several articles on this subject, which IPIF can send reprints of to those who are interested. Dr. Goldberg is also a member of the Scientific Advisory Council of the Incontinentia Pigmenti International Foundation.

Incontinentia Pigmenti International Foundation

Laura M Richter | President and CEO

Susanne Bross Emmerich | Founder

Tel: 212 452-1231 Fax: 212 452-1406

E-Mail: ipif@ipif.org

30 East 72nd Street ♦ Suite 16 ♦ New York, New York 10021 ♦ U.S.A

Mailing Address -

78 Saint Moritz Drive, Erial, New Jersey 08081, U.S.A

www.ipif.org