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20 - National registry for childhood glaucoma in Germany: Feasibility study, clinical care and research (pilot study)

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Purpose: The aim is to investigate epidemiological data, risk factors and treatment of childhood glaucoma in Germany. For this purpose, an initial database to register patients diagnosed with different types of childhood glaucoma was established from 2017 until 2019 as part of a prospective clinical cohort study. The intention is to create a national registry for childhood glaucoma in Germany.
Methods: 28 children with different types of childhood glaucoma, who were admitted and treated at the Childhood Glaucoma Centre of the University Medical Centre, Mainz, Germany, were included. Documents and questionnaires for the acquisition and storage of epidemiological and clinical data were developed and checked for feasibility and practicability in the clinical routine. Furthermore, each child and their parents were offered genetic testing for known genes that cause childhood glaucoma. The test was carried out in cooperation with the Institute of Human Genetics of the University Medical Centre in Mainz and was paid for by the statutory health insurance.
Results: The individual documents and questionnaires included: Informed consent form from the parents, medical history form of the child, patient's gestational history questionnaire and examination form of the examination under general anaesthesia (EUAF). Primary congenital glaucoma (PCG) and secondary childhood glaucoma (SCG) were revealed in 11 (39.3%) and 17 (60.7%) patients, respectively. The most common cause of SCG was Peters anomaly (41.2%). Bilateral glaucoma was diagnosed in 81.8% (PCG) and 58.8% (SCG) of all patients. The mean intraocular pressure (IOP) measured with a Perkins tonometer in all patients with childhood glaucoma at the time of inclusion was 17.5±11.8 mmHg in the right and 17±8.9 mmHg in the left eye, respectively. In 33.3% of the children mainly these four genes, which are associated with childhood glaucoma, were found: *CYP1B1*, *FOXC1*, *LTBP2* and *TEK*.
Conclusions: This pilot study showed good feasibility of data acquisition of glaucoma children and their parents including individually developed

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documents and questionnaires to provide detailed unique baseline data for a national registry on different types of childhood glaucoma in Germany. In the near future, registry data will provide valuable information to identify new risk factors for childhood glaucoma and evaluate different treatments under real-life conditions in Germany.