Zespół Aperta – grupy wsparcia

Kasia Więckowska

SKN Kardiologii Prenatalnej

12 sierpnia 2016 r.

Zespół Aperta – grupy wsparcia – POLSKA

Stowarzyszenie na Rzecz Dzieci z Rzadkimi Chorobami Genetycznymi i Ich Rodzin Wspólnie

ul. Chałubińskiego 3
50-369 Wrocław, Polska

stowarzyszenie@wspolnie.org

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martadomanska.pl

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Dane o szpitalach:

Instytut Matki i Dziecka w Warszawie

Poradnia Chirurgiczna

tel. rejestracja: 22 32 77 050 lub 22 32 77 051

od poniedziałku do piątku w godz. 8^{00} - 15^{35}

Klinika w Bogenhausen w Monachium, Niemcy

(operacje twarzoczaszki)

tel. rejestracja: 0049 8992702031

Dr. Steven von Gernet (chirurg przeprowadzający konsultacje i wykonujący operacje)

Katholisches Kinder Krankenhaus Wilhelmstift w Hamburgu, Niemcy

(operacje rozdzielenia paluszków)

tel. rejestracja: 0040 67377254

mail: handchirurgie@kkh-wilhelmstift.de

Dr. Rolf Habenicht (kierownik oddziału)

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Choroby rzadkie

Lista chorób rzadkich SŁOWNIK (ultra)rzadkie SWAN Pobierz

wtorek, 14 sierpnia 2012

Zespół Aperta

Zespół Aperta to rzadki zespół wad wrodzonych, obejmujący defekty w obrębie czaszki, kości rąk i stóp. Inne objawy obserwowane w przebiegu życia dziecka wynikają z nieprawidłowości w szkielecie. Zespół dziedziczony jest w sposób autosomalny dominujący, a jego nazwa pochodzi od nazwiska lekarza, który podał najdokładniejszy opis choroby – Eugena Aperta. Dokonał tego w roku 1906, a więc stosunkowo „niedawno".

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Supporting families with a craniofacial condition in the UK and overseas

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Headlines' Leaflets

- Aperts Syndrome
- Craniofrontonasal Syndrome
- Crouzon Syndrome
- Muenke Syndrome
- Pfeiffer Syndrome
- Saethre-Chotzen Syndrome
- Single Suture Craniosynostosis
- What causes Craniosynostosis? - a general discussion, with a focus on genetic aspects (syndromes)
- The Surgical Treatment of Hand Anomalies associated with Craniofacial Conditions
- Glossary of Terms associated with Craniosynostosis
- Breathing Problems in Craniofacial Syndromes
- Eye Aspects of Craniofacial Conditions
- Positional Plagiocephaly (Occipital or Deformational Plagiocephaly)

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Specialist Hospitals

There are four 'National Craniofacial Units' designated to provide specialist services for children and adults born with craniofacial problems in the United Kingdom:

- Alder Hey Children's Hospital, Liverpool
- Birmingham Children's Hospital, Birmingham
- Great Ormond Street Hospital for Children, London
- Oxford Children's Hospital.

The Units aim to provide patients with co-ordinated treatment. Alongside their craniofacial expertise they work with other departments within the hospitals and the local community tailored to suit each patient. This should help patients and their carers to access the full range of disciplines and services they need to treat the various conditions.

Referrals by GPs are accepted at Liverpool, Birmingham and Oxford. However, Great Ormond Street, London requires referrals made via paedriatricians or other hospital consultants.

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Apert syndrome

Go back a step

Print

Background

Apert syndrome is a rare genetic condition characterised by abnormal craniofacial (skull and face) development and severe fusion of skin and bones between the individual fingers and toes.

Credits

Last updated October 2015 by Professor A Wilkie, Nuffield Professor of Pathology, Weatherall Institute of Molecular Medicine, Oxford University, Oxford, UK.

Grupy wsparcia – USA

FACES

FACES: The National Craniofacial Association

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Contact Us

Craniofacial Anomalies

Medical Centers

Paying the Bills

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Craniofacial Disorders

Apert Syndrome
Basal Cell Carcinoma Nevoid Syndrome (Gorlin Syndrome & Basal Cell Nevus Syndrome)
Carpenter Syndrome
Cleft Lip and Palate
Cleidocranial Dysplasia
Craniosynostosis
Crouzon Syndrome
Freeman Sheldon Syndrome
Goldenhar Syndrome
Hallerman-Streiff Syndrome
Hemifacial Microsomia
Hydrocephalus
Microtia
Moebius Syndrome
Nager Syndrome
Miller Syndrome
Nasal Encephaloceles
Neurofibromatosis
Orbital Hypertelorism
Parry-Romberg Syndrome
Pfeiffer Syndrome

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W zakładce „Medical Centers” można znaleźć ośrodki odpowiednie dla każdego ze stanów, w których możliwe jest wykonanie zabiegów chirurgicznych

http://www.faces-cranio.org/MedCent.htm

Grupy wsparcia – USA

NORD®
National Organization for Rare Disorders

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0-9 • A • B • C • D • E • F • G • H • I • J • K • L • M • N • O • P • Q • R • S • T • U • V • W • X • Y • Z Print

Apert Syndrome

Synonyms of Apert Syndrome

- Acrocephalosyndactyly, Type I
- ACS1
- ACS I
- Syndactylic Oxycephaly

General Discussion

Apert syndrome, also known as acrocephalosyndactyly type I (ACS1), is a rare genetic disorder that is apparent at birth (congenital). The disorder is character-ized by distinctive malformations of the head that lead to distinctive facial features. In addition, the hands and/or feet may webbed (syndactyly) and in some cases, mental

Report Index

Synonyms
General Discussion
Signs & Symptoms
Causes
Affected Populations
Related Disorders
Standard Therapies
Investigational Therapies
Resources
Supporting Organizations
References

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http://rarediseases.org/rare-diseases/apert-syndrome/#supporting-organizations

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Apert International, Inc.
Post Office Box 2571
Columbia, SC 29202
803-732-2372
www.apert-international.org

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General Donations

Checks mailed to our PO Box also gratefully accepted.

Thank you!!!

http://www.apert.org