

NADF RESOURCE LIST

(Updated 4/11/08)

ADDISON & CUSHING INTERNATIONAL FEDERATION (ACIF)

<http://www.nvacp.nl/page.php?main=5>

Addison's Disease Self Help Group (UK)

<http://www.adshg.org.uk/index.html>

Registered address: 21 George Road, Guildford, Surrey, GU1 4NP

President: Mrs Deana Kenward. Email: deana@adshg.org.uk

Adrenal Cancer Support

<http://www.adrenalcancersupport.org/>

info@adrenalcancersupport.org

The Adrenoleukodystrophy Foundation

<http://www.aldfoundation.org/>

739 Michigan Avenue

Slidell, LA 70458

Phone:

985-645-9559

E-Mail:

General Inquiries:

info@aldfoundation.org

David Cry, CEO:

davidcry@aldfoundation.org

APS Type 1

(APS Type 1) Autoimmune Polyglandular Syndrome Type 1, also known as (APECED) Autoimmune polyendocrinopathy-candidiasis-ectodermal dystrophy.

APStype1.org

The ATAC Research Fund

Advancing Treatments for Adrenocortical Carcinoma

c/o TGen Foundation

400 N. 5th Street, Suite 1650

Phoenix, AZ 85004

480-600-9950

<http://www.atacfund.org>

info@atacfund.org

American Association of Clinical Endocrinologists (AACE)

1000 Riverside Ave.; Suite 205

Jacksonville, FL 32204

Voice: (904) 353-7878

Fax: (904) 353-8185

<http://www.aace.com/>

If you need to obtain the name of an endocrinologist in your area, please see our Find an Endocrinologist page <http://www.aace.com/memsearch.php>

American Autoimmune Related Diseases Association, Inc. (AARDA)

22100 Gratiot Ave

Eastpointe MI 48021-2227

810-776-3900

800-598-4668

e-mail: aarda@aol.com

Home Page: <http://www.aarda.org/>

American Diabetes Association

For diabetes-related questions or to request a diabetes information packet, email them at AskADA@diabetes.org. In order to better serve you, please provide your name and address along with your request.

You can also call the American Diabetes Association at 1-800-DIABETES (1-800-342-2383). Their hours of operation are Monday - Friday, 8:30 AM - 8 PM Eastern Standard Time.

Or write:

American Diabetes Association

ATTN: National Call Center

1701 North Beauregard Street

Alexandria, VA 22311

American Foundation of Thyroid Patients

<http://www.thyroidfoundation.org>

4322 Douglas Ave.

Midland, TX 79703

thyroidfoundation.org

American Thyroid Association

6066 Leesburg Pike, Suite 550

Falls Church, Virginia 22041

phone: 703 998-8890

fax: 703 998-8893

e-mail: admin@thyroid.org

web site: www.thyroid.org

For Patients:

1-800-THYROID

<http://www.thyroid.org/patients/index.html>

Androgen Insensitivity Support Group

P.O. Box 2148

Duncan, OK 73534-2148

(802) 295-6017

aissgusa@hotmail.com

Association "SURRENALES"

French Adrenal Diseases Organization

Addison's disease, Cushings' CAH and other related disorders

6 rue du Prieuré - 91100

Corbeil-Essonnes, France

Website: <http://www.orpha.net/nestasso/AGS/frame.html>

Contact: surrenales@aol.com.

téléphone : 01 64 96 13 59

Associazione Italiana Pazienti Addison (AIPAd)

Italian Association for Addison patients

Via del Dosso, 5

20040 Usmate Velate (MI) Italy

e-mail antocampo@tin.it

contact : Mrs. Antonella Campodall'Orto

www.morbodiaddison.org

Australian Addison's Disease Association Inc.

<http://www.addisons.org.au/>

Sue O'Brien (Secretary)

E-mail: secretary@addisons.org.au

Tel: (02) 6657-2571 (+61 2 6657-2571 outside Australia)

Fax: (02) 6657-1025 (+61 2 6657-1025 outside Australia)

Post: P.O. Box 297

Dorrigo, NSW 2453

Australia

or:

Noreen Secomb (President)

Tel: (02) 6652-4761 (+61 2 6652-4761 outside Australia)

Post: P. O. Box 2436

Coffs Harbour NSW 2450

Australia

Help-line (02) 6652-4761

Binder & Binder® Social Security Disability Advocates®

National Headquarters

215 Park Avenue South

6th Floor

New York, New York 10003

Telephone: 800.742.9696

Fax: 212.677.0423

Information@BinderandBinder.com

Questions@BinderandBinder.com

The Canadian Addison Society

193 Elgin Avenue West

Goderich, ON N7A 2E7

1-888-550-5582

<http://www.addisonsociety.ca>

Canadian Organization for Rare Disorders

P.O. Box 814

Coaldale, Alberta

Canada T1M 1M7

Phone: (403) 345-4544

Fax: (403) 345-3948

Toll Free: 1-877-302-7273

<http://www.cord.ca/>

Cancer Treatment Centers of America

Corporate Office:

1336 Basswood Road

Schaumburg, IL 60173 Available 24 Hours

<http://www.cancercenter.com/>

800-931-0599

CARES Foundation, Inc.

(Congenital Adrenal hyperplasia Research, Education and Support)

2414 Morris Ave., Suite 110

Union, NJ 07083

Office: (973) 912-3895

Toll free: (866) 227-3737

Fax: (973) 912-8990

Email: kelly@caresfoundation.org

Website: www.caresfoundation.org

Department of Health and Human Services (HHS)

Centers for Disease Control

1600 Clifton Road, N.E.

Atlanta, GA 30333 USA

Tel: (404) 639-3311

Public Inquiries: (404) 639-3534 / (800) 311-3435

<http://www.cdc.gov/>

CLIMB, Children Living With Inherited MetaBolic Diseases

Congenital Adrenal Hyperplasia Support Group

United Kingdom

Website: <http://www.cah.org.uk>

webmaster@cah.org.uk

0870 7700326 for Support Services, or

0870 770325 for Admin & Fundraising

Weill Cornell Medical Center

New York-Presbyterian Hospital

525 East 68th Street

New York, NY 10021

(212) 746-5454, Main Number

doctor referral: 1-877-CORNELL

Cushing's Support and Research Foundation

65 E India Row, #22B

Boston MA 02110

Phone: 617-723-3674

Fax: 617-723-3674

e-mail: cushinfo@csrf.net

Home Page: <http://www.csrf.net/index.htm>

eMedicine from WebMD

<http://www.emedicine.com/>

The Endocrine Society

<http://www.endo-society.org>

Admin. Asst., Public Affairs

4350 East West Highway, Suite 500x

Bethesda, MD 20814

T: 301-941-0251

F: 301-941-0259

bcoble@endo-society.org

Doctor Referral: 1-800-HORMONE or email your request to

referrals@endo-society.org

EndocrineWeb.com

<http://www.endocrineweb.com/>

Glaucoma Research Foundation

251 Post Street, Suite 600

San Francisco, CA 94108

415-986-3162

Toll-free: 800-826-6693

<http://www.glaucoma.org/>

Health and Social Campaigners' Network International

Contact details for PatientView

Woodhouse Place

Upper Woodhouse

Knighton

Powys, LD7 1NG

Wales

Tel: +44-(0)1547-520-965

Fax: +44-(0)1547-528-501

email: info@patient-view.com

Internet: www.patient-view.com

The Hormone Foundation

The public education affiliate of The Endocrine Society

8401 Connecticut Ave

Suite 900

Chevy Chase, MD 20815

301-941-0256

www.hormone.org

Hypoglycemia Support Foundation, Inc.

PO BOX 451778

Sunrise, FL 33345

<http://www.hypoglycemia.org/default.asp>

Intersex Society of North America

979 Golf Course Drive #282

Rohnert Park CA 94928

Fax: (801) 348-5350

<http://www.isna.org/>

Loyola University Health System

2160 South First Avenue

Maywood, Illinois 60153

Healthcare Access Call Center: (708) 216-8563

General Information: (708) 216-9000

Patient Information: (708) 216-3793

Physician Referral: (708) 327-1000

Mayo Clinic

507-284-2511

Rochester, MN

<http://www.mayo.edu/>

Medic Alert Foundation

2323 Colorado Avenue

Turlock CA 95382

209-668-3333

800-432-5378

e-mail: Inquiries@medicalert.org

Home Page: <http://www.medicalert.org>

Morbus Addison Foreningen Denmark

Website: <http://www.addison.dk>

Contact: Valgren Jochumsen

Skovbrynet 2, 7183

Randbøl, Denmark

telephone: 75 88 35 32

mail@addison.dk

Multidisciplinary Adrenal Cancer Clinic

University of Michigan Comprehensive Cancer Center

1500 E. Medical Center Drive

CCGC 6-303

Ann Arbor, MI 48109-0944

Cancer Center on Floor B1, Reception C.

Cancer AnswerLine 800-865-1125

<http://www.cancer.med.umich.edu/clinic/adrenalclinic.htm>

National Alopecia Areata Foundation

PO Box 150760

San Rafael, CA

94915-0760

415.472.3780

Fax 415.472.5343

<http://www alopeciaareata.com/default2.asp>

National Institute of Health Office of Rare Disorders

6100 Executive Boulevard, 3B-01

Bethesda, Maryland 20892-7518

Telephone: (301) 402-4336

Fax: (301) 480-9655

ord@od.nih.gov

<http://rarediseases.info.nih.gov/>

Rare Diseases Clinical Research Network (RDCRN)

<http://rarediseasesnetwork.epi.usf.edu/>

Rare Genetic Steroid Disorders Consortium

<http://rarediseasesnetwork.epi.usf.edu/rgsdc/index.htm>

All Administrative Concerns Can be Addressed to:

Maria I. New, MD

Professor of Pediatrics

Pediatric Endocrinology

Director, Adrenal Steroid Disorders Program

The Mount Sinai School of Medicine

One Gustave L. Levy Place, Box 1198

New York NY 10029-6574

E-mail: maria.new@mssm.edu

National Organization for Rare Disorders

55 Kenosia Avenue

PO Box 1968

Danbury, CT 06813-1968

(203) 744-0100

Tollfree: (800) 999-6673 (voicemail only)

TDD Number: (203) 797-9590

Fax Number:

(203)798-2291

orphan@rarediseases.org

<http://www.rarediseases.org/>

Nederlandse Vereniging voor Addison en Cushing Patiënten (NVACP) Dutch Addison and Cushing Society (NVACP)

Addison's disease, Cushing syndrome, CAH/AGS, Conn's syndrome

A. Noordzij

Fazantpad 3

3766 JH Soest

The Netherlands

Website: <http://www.nvacp.nl/>

Contact: Mrs Alida Noordzij, info@nvacp.nl

tel. +31 (35) - 60 12700

+31 (35) - 58 25460

Netzwerk Hypophysen- und Nebennierenerkrankungen e.V.

German Pituitary and Adrenal Network

All pituitary and adrenal diseases

Waldstraße 34
91054 Erlangen, Germany
Contact: netzwerk@glandula-online.de
Internet: www.glandula-online.de
Tel: [+49] (0)9131 / 815046
Fax: [+49] (0)9131 / 815047

NYU Medical Center and School of Medicine

General Contact Information

550 First Avenue
New York, NY 10016
(212) 263-7300
Patient Information
(212) 263-7300

New Zealand Addison's Network (NZAN)

Website: <http://www.addisons.org.nz>
Contact: info@addisons.org.nz
Jeanette Crossley, jeanette.c@paradise.net.nz

The North American Menopause Society

5900 Landerbrook
Drive, Suite 195
Mayfield Heights,
OH 44124
Mail Address
Post Office Box 94527
Cleveland, OH 44101
Email
info@menopause.org
Tel: 440/442-7550
Fax: 440/442-2660
<http://www.menopause.org/default.htm>

Pheochromocytoma Organization

<http://www.pheochromocytoma.org>
Debra Harlander
धारlander@twcny.rr.com
Mary Peebels
ThreePeb@aol.com

Pituitary Disorders Education & Support

Phone: (810) 227-2715
PDES P.O. BOX 571
Brighton , MI 48116
<http://pituitarydisorder.net/>

The Pituitary Foundation

P.O. Box 1944
Bristol

BS99 2UB, UK

Website: <http://www.pituitary.org.uk>

Contact: helpline@pituitary.org.uk

Tel/fax: 0845 450 0375

Pituitary Network Association

223 East Thousand Oaks Blvd., #320

Thousand Oaks, CA 91360

(805) 496-4932

Fax: (805) 557-1161

<http://www.pituitary.com/>

Polycystic Ovarian Syndrome Association

P.O. Box 3403

Englewood, CO 80111

info@pcosupport.org

877-775-PCOS

<http://www.pcosupport.org/>

Premature Ovarian Failure Support Group

Regular Mail: POF Support Group

PO Box 23643

Alexandria, VA 22304

Support Line: 703-913-4787

<http://www.pofsupport.org/>

Quest Diagnostics

1290 Wall Street West

Lyndhurst, NJ 07071

800-222-0446

<http://www.questdiagnostics.com/>

Jeffrey Rabin & Assoc., Ltd.

Jeffrey A. Rabin

Disability Lawyer

640 Pearson St., #300

Des Plaines, IL 60016

jeff@rabinsslaw.com

847-299-0008

Sjögren's Syndrome Foundation

8120 Woodmont Ave.

Suite 530

Bethesda, MD 20814

Information Requests:

Tel: (301) 718-0300

Fax: (301) 718-0322

<https://www.sjogrens.org/>

**Stanford University
Stanford Hospital & Clinics**

300 Pasteur Drive
Stanford, California 94305
(650) 723-4000
Referral Center (800) 756-9000
referral@stanfordmed.org

Stödföreningen Hypophysis

Swedish adrenal and pituitary disease organization
Sandhult 7225
280 40 Skånes Fagerhult, Sweden
Website: <http://come.to/hypophysis>
Contact: Mrs. Pia Lindström, Hypo.physis@orkelljunga.mail.telia.com
Tele: 0433- 309 95

Thyroid Federation International

Headquarters: 797 Princess St., Suite 304
Kingston, ON K7L 1G1 Canada
Tel: 1-613-544-8364
Fax: 1-613-544-9731
e-mail: tfi@on.aibn.com
<http://www.thyroid-fed.org/>

Thyroid Foundation of America

One Longfellow Place, Suite 1518
Boston, MA 02114
Phone: 800-832-8321
Fax: 617-534-1515
Email: info@allthyroid.org
<http://www.tsh.org/>

Trover Health System

900 Hospital Drive
Madisonville, KY 42431
1-800-998-5100
270-825-5100
<http://www.troverhealth.org/>

United Leukodystrophy Foundation

2304 Highland Drive
Sycamore, IL 60178
(800) 728-5483
e-mail: office@ulf.org
website: www.ulf.org

**Vanderbilt University Medical Center
Pituitary Center**

Address:
Suite 2501 TVC

Nashville, TN
37232-5100
Appointments:
615-343-7146
Fax:
615-343-4953
Lewis.Blevins@mcm.vanderbilt.edu

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505 Northern Blvd., Suite 200
Great Neck, NY 11021
(516) 487-4992
NADFMAIL@aol.com
www.nadf.us

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