



INTERNATIONAL SJÖGREN'S NETWORK

www.internationalsjogrensnetwork.org

**Edited by the AFGS (France)
Updated January 2010**

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Warning: This yearbook is provisional. Please check that all your data are correct. The phone numbers have been standardized and the international dialling code added. Should you find any mistake, please contact the AFGS.

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AUSTRIA

Name and acronym	Selbsthilfe-Gruppe « La Vera » Sjogren-Syndrom
First established in	2006
Address	Vera Pekarek c/o La Vera Image Partyservice und Catering GmbH A-1130 Wien Orangerie Schönbrunn Schönbrunner Schloßstraße 47
e-mail address	vera.pekarek@imagevienna.com
Phone	+43 664 325 5797
Fax	+43 181 250 4188
Web site	www.sjogren-syndrom.at
Communication languages	German and a little bit English
Chairman name	Private
Number of members	
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Only Sjögren's Syndrome
Supports research?	No
Newsletter (name, periodicity, paper and/or electronic version)	No
Last updated	Summer 2009

AUSTRALIA

Name and acronym	The Australian Sjögren's Syndrome Association Inc. (TASSA)
First established in	2001
Address	39 Main Arm Rd, Mullumbimby 2482
e-mail address	bevnorton@sjogrens.org.au
Phone	+61 (0) 26 684 3704
Fax	N/A
Web site	www.sjogrens.org.au
Communication languages	English
Chairman name	Mrs. Beverly NORTON
Number of members	150
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Sjögren's and all associated diseases
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Australian moisture seekers
Last updated	Summer 2009

CANADA

Name and acronym	Sjögren's Society of Canada, SjSC
First established in	2006
Address	32 Oneida Drive, Brantford, Ontario, Canada N3S 0A8
e-mail address	info@sjogrenscanada.org or leedurdon@rogers.com
Phone	+1 416 943 8150
Fax	+1 519 752 3830
Web site	www.sjogrenscanada.org
Communication languages	English
Chairman name	Mrs.Lee DURDON, President & Founder
Number of members	1200 and growing
Only Sjögren's association in the country	Only national. There is a separate organization in Quebec.
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Dedicated Exclusively to Sjögren's
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	"Connections", magazine style – paper, published quarterly
Last updated	Summer 2009

CANADA QUEBEC

Name and acronym	Association du Syndrome de Sjögren Inc
First established in	Sept. 1994
Address	3155 Rue Hochelaga, Suite 001, Montréal, Quebec, Canada H1W 1G4
e-mail address	sjogren.montreal@qc.aira.com
Phone	+1 514 934 3666
Fax	+1 514 934 1241
Web site	www.sjogrens.ca
Communication languages	French and English
Chairman name	Mrs. Ginette TEXIER
Number of members	210
Only Sjögren's association in the country	No
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Exclusively to Sjögren's
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Sjögren's bulletin, quarterly, paper version only
Last updated	Spring 2009

FINLAND

Name and acronym	Sjögrenin syndrooma -yhdistys ry
First established in	1996
Address	Kauppakatu 1 A, 60100 Seinäjoki, Finland
e-mail address	ssyhdist@kolumbus.fi
Phone	+358 6 4232014
Fax	
Web site	www.kolumbus.fi/sjogrenin.syndrooma
Communication languages	Finnish, Swedish
Chairman name	Mrs. Marja-Liisa PELTONEN
Number of members	2490
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	exclusively SS
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Kuivakukat, quarterly 28-page magazine, paper. Partly electronic Leaflets in Finnish, Swedish, Estonian, English, yearly updated
Last updated	Spring 2009.

FRANCE

Name and acronym	Association Française du Gougerot-Sjögren et des Syndromes Secs AFGS
First established in	1990
Address	Les Peyrières, 81660 Pont de l'Arn. France
e-mail address	afgs@wanadoo.fr
Phone	+33 (0) 56 361 0470
Fax	+33 (0) 56 361 0470
Web site	www.afgs-syndromes-secs.org
Communication languages	French
Chairman name	Mrs Catherine FAOU
Number of members	2350
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Sjögren's exclusive
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	"Ressources", Quarterly, paper
Last updated	Spring 2009

GERMANY

Name and acronym	Selbsthilfe-Netzwerk Sjögren-Syndrom
First established in	May 1999
Address	Elfriede Borchers, Schäferbergweg 11, D-71069 Sindelfingen
e-mail address	ebo@borchers.org
Phone	+49(0)7031-386202
Fax	+49(0)7031-382595
Website	www.sjoegren-erkrankung.de
Communication languages	German and English
Chairman name	
Number of members	
Only Sjogren's association in the country	
Dedicated exclusively to Sjogren's or also dedicated to other rheumatic diseases	Only Sjögren-Syndrom
Supports research?	
Newsletter (name, periodicity, paper and/or electronic version)	No
Last updated	

INDIA

Name and acronym	Sjögren's India (SI)
First established in	2006
Address	701, Vatsaraj, Opposite Shraddha School, Jodhpur Gam Road, Ahmedabad – 380015 Gujarat India
e-mail address	kirtidaoza@gmail.com kirtidaoza@hotmail.com purvid@gmail.com
Phone	+91 792 692 2254 and +91 942 913 3344
Fax	none
Web site	www.sjogrensindia.org
Communication languages	English, Hindi, Gujarati
Chairman name	Mrs. Kirtida OZA
Number of members	Registered members : 20 patients (Gujarat State) + 1 family member each Unregistered patients above 50 across India
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Yes But have been extending counselling support to patients suffering from RA, Lupus, Scleroderma
Supports research?	Not yet but would like to would also like to take up advocacy issues
Newsletter (name, periodicity, paper and/or electronic version)	Not yet... working on development of multi lingual website
Last updated	Summer 2009

ISRAEL

Name and acronym	Israeli Association of Sjögren's Syndrome
First established in	1990
Address	Mevo Timna 6B, Jerusalem 97753, Israel
e-mail address	be.porath@gmail.com :
Phone	+972 2-5813011
Fax	+972 2-5817724
Web site	---
Communication languages	English and Hebrew
Chairman name	Dr. (Mrs.) Natanli STERMAN
Number of members	100 paid membership ; 50 complimentary ; and 200 invitees for our yearly conference
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Exclusively to Sjögren's but include relatively related articles in the journal we publish 3 times a year
Supports research?	We are saving for this
Newsletter (name, periodicity, paper and/or electronic version)	"Yedion" ; 3 times a year ; 35-40 pages each in English and Hebrew on A-4 paper
Last updated	Summer 2009

ITALY

Name and acronym	Associazione Nazionale Italiana Malati Sindrome di Sjögren - A.N.I.Ma.S.S.
First established in	18/04/2005
Address	Via S.Chiera, 6 37129 Verona - ITALIA
e-mail address	Animass.sjogren@fastwebnet.it
Phone	+39 333 838 6993 - +39 045 958 0027
Fax	+39 045 958 0027
Web site	http://www.animass.org/sjogren
Communication languages	Italian
Chairman name	Dr. (Mrs) Lucia MAROTTA
Number of members	1.000
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Sjögren's syndrome exclusive
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	
Last updated	Summer 2009

JAPAN

Name and acronym	Japanese Sjögren's Association for Patients, JSAP
First established in	1986
Address	Nihon University Scholl of Medicine 30-1 Oyaguchitanimachi Itabashiku Tokyo 173-8610 Japan
e-mail address	sjogren@med.nihon-u.ac.jp
Phone	+81 (0)3 3972 8111 Ext 2402 (Dr Masami Takei)
Fax	+81 (0)3 3972 2893
Web site	http://www.maeda-shoten.com/sjogren/
Communication languages	Japanese
Chairman name	Mrs. Chizuko NAKADA (Yoko TOKUNO, secretary)
Number of members	400
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Sjögren's syndrome exclusive
Supports research?	No
Newsletter (name, periodicity, paper and/or electronic version)	Year report, 1/Y Communication letter, 2/Y
Last updated	Winter 2009

KOREA

Name and acronym	Korea Sjogren's syndrome Support Group(KSSG)
First established in	2002.05.25
Address	Korea, Gyeonggi-do, Hwaseong-si, Anneaung-dong 210, Chung Kwang APT 102-904
e-mail address	sjogren@dreamwiz.com
Phone	
Fax	
Web site	http://www.sjogren.or.kr
Communication languages	korean
Chairman name	Choi Kyung-seok
Number of members	150 persons
Only Sjogren's association in the country	Yes
Dedicated exclusively to Sjogren's or also dedicated to other rheumatic diseases	Only sjogren's
Supports research?	NO
Newsletter (name, periodicity, paper and/or electronic version)	YES
Last updated	Winter 2009

NEW ZEALAND

Name and acronym	Sjogrens Syndrome Association of New Zealand
First established in	(approx) 1994 as support group Incorporated Society Established 2007
Address	Bldg 1, Unit C, 3 Ceres Court, Albany, Auckland North Shore 0632
e-mail address	sarah@sjogrensnewzealand.co.nz
Phone	+64 (0)9 478 1578
Fax	
Web site	www.sjogrensnewzealand.co.nz
Communication languages	English
Chairman name	David ZIMMERMAN
Number of members	approx 800
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Yes
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	New Zealand Sjögren's Syndrome Association Newsletter. About monthly-mostly posted paper version, some sent electronically
Last updated	Summer 2009

SPAIN

Name and acronym	Asociación Española de Síndrome de Sjögren (AESS)
First established in	1995
Address	C/ Cea Bermúdez, 14A Piso 6 Of. 2. 28003 Madrid Spain
e-mail address	info@aesjogren.org
Phone	+34 91 535 8653
Fax	+34 91 535 8654
Web site	www.aesjogren.org
Communication languages	Spanish
Chairman name	Jenny Inga DIAZ
Number of members	420
Only Sjögren's association in the country	No
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Sjögren's exclusive
Supports research?	No
Newsletter (name, periodicity, paper and/or electronic version)	"Gota a Gota" magazine. Yearly
Last updated	Summer 2009

SWEDEN

Name and acronym	Riksföreningen Sjögrens Syndrom
First established in	1985
Address	Box 147, S-233 23 Svedala, Sweden
e-mail address	harry.paulnitz@telia.com
Phone	+46 4625 5925
Fax	+46 4040 1535
Web site	www.sjogrensyndrom.se
Communication languages	Swedish and english
Chairman name	Harry FH PAULNITZ
Number of members	1.400 paying members and 3.200 gets our newsletter
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	We are only dedicated to Sjögren's.
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Medlemstidningen Sjögrens syndrome. Earlier called Torkarbladet.
Last updated	Summer 2009

SWITZERLAND

Name and acronym	Association Romande du Syndrome de Sjögren, ARSYS
First established in	2007
Address	Rue du Simplon 30, 1800 Vevey, CH
e-mail address	info@sjogren.ch
Phone	+41 21 921 2931
Fax	-
Web site	www.sjogren.ch
Communication languages	French (German and English spoken)
Chairman name	Mrs. Alice GROSJEAN
Number of members	15
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Only Sjögren's
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Bulletin, twice a year, paper
Last updated	Summer 2009

THE NETHERLANDS

Name and acronym	Nationale Vereniging Sjögrenpatiënten NVSP
First established in	10 december 1986
Address	Visitors address ; Stationsweg 16, 3981 AC Bunnik Post address ; Postbus 4, 3980 CA Bunnik
e-mail address	info@nvsp.nl
Phone	+ 31 (0)30 294 1383
Fax	+31 (0)30 294 8503
Web site	www.nvsp.nl
Communication languages	Dutch
Chairman name	Mrs. Nanda LUBERTSEN
Number of members	2231
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Sjögren's Syndrome exclusively
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	'n Ogenblikje, quarterly, paper
Last updated	Summer 2009

UNITED KINGDOM

Name and acronym	British Sjögren's Syndrome Association BSSA
First established in	1986
Address	Po Box 15040, Birmingham B31 3DP
e-mail address	office@bssa.uk.net
Phone	+ 44 (0) 121 455 6532
Fax	
Web site	www.bssa.uk.net
Communication languages	English
Chairman name	Mrs. Linda J Stone
Number of members	2300
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Just Sjögren's Syndrome
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Quarterly newsletter - paper
Last updated	Summer 2009

USA

Name and acronym	Sjögren's Syndrome Foundation (SSF)
First established in	1983
Address	6707 Democracy Blvd, Ste 325
e-mail address	ssf@sjogrens.org
Phone	+1 301 530 4420
Fax	+1 301 530 4415
Web site	www.sjogrens.org
Communication languages	England
Chairman name	Mr. Steven TAYLOR (CEO)
Number of members	10,000+ ; Mail to 12,000
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Yes
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	<i>The Moisture Seekers</i> ; paper; for patient readers <i>Sjögren's Quarterly</i> ; paper and electronic for international audience; targets professional readers, but patients may subscribe as well
Last updated	Spring 2009

FRANCE SCLERODERMA

Name and acronym	Association des Sclérodermiques de France A.S.F.
First established in	1989
Address	41 rue du Pont de Fer – 28260 Sorel-Moussel France
e-mail address	association.asf@club-internet.fr
Phone	+ 33 (0) 82 062 0615
Fax	
Web site	www.association-sclerodermie.fr
Communication languages	French
Chairman name	Mrs. Dominique GODARD
Number of members	1000
Only Sjögren's association in the country	
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Scleroderma
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Quarterly paper and a newsletter in a few months time
Last updated	Summer 2009

**INTERNATIONAL PAINFUL BLADDER
(BASED IN THE NETHERLANDS)
PATIENT ORGANIZATION FOR AN ASSOCIATED DISORDER**

Name and acronym	International Painful Bladder Foundation IPBF
First established in	2005
Address	B.L.F. De Montignylaan 73, 3055 NA Rotterdam, The Netherlands
e-mail address	info@painful-bladder.org
Phone	+31 (0)10 461 3330
Fax	Same
Web site	www.painful-bladder.org
Communication languages	English + information leaflets in many other Languages
Chairman name	Mrs. Jane MEIJLINK
Number of members	5 board members worldwide. Subscription to the newsletter is free (around 5000 subscribers).
Only Sjögren's association in the country	-
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	This foundation is dedicated to interstitial cystitis and associated disorders, including SS. We have a book on Sjögren's Syndrome by Dr Joop P van de Merwe on our website: http://www.painful-bladder.org/pbs_ic_ass_dis.html
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Quarterly IPBF e-newsletter
Last updated	Summer 2009

POLAND RHEUMATIC DISEASES

Name and acronym	Association of People with Rheumatism and their Friends (Stowarzyszenie Reumatyków i ich Sympatyków)
First established in	1993
Address	Spartanska 1, 02-637 Warsaw, Poland
e-mail address	reuma@idn.org.pl
Phone	+48 664 630 125
Fax	
Web site	http://reuma.idn.org.pl
Communication languages	Polish, English, Russian
Chairman name	Mrs. Jolanta GRYGIELSKA
Number of members	300
Only Sjögren's association in the country	No association only for people with Sjogren syndrome
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	For people with every rheumatic disease
Supports research?	No
Newsletter (name, periodicity, paper and/or electronic version)	"Golden Remedy" (Złoty Srodek) twice a year, paper and electronic version
Last updated	Summer 2009

PORTUGAL LUPUS

Name and acronym	Associação de Doentes com Lúpus (Portuguese Lúpus Patients' Association) - ADL
First established in	January 1992
Address	Praça João do Rio 9 r/ dto 1000/ 180 Lisboa Portugal
e-mail address	associacao.lupus@clix.pt
Phone	+351 21 844 6473
Fax	+351 21 314 6216
Web site	Being renewed
Communication languages	English, Portuguese, French
Chairman name	Rosa Maria GONCALVES
Number of members	3000
Only Sjögren's association in the country	
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Dedicated to Lúpus disease
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Being remodelled
Last updated	Summer 2009

RUSSIA RHEUMATIC DISEASES

Name and acronym	Interregional Non-Government Organization of Invalids Rheumatologic Association "Nadezhda" RRA "Nadegda"
First established in	2006, Russia
Address	Russia, Moscow, Kashirskoe shosse, h.34 a
e-mail address	Buna17@mail.ru
Phone	+8 (495) 338-46-25
Fax	+8 (495) 338-46-25
Web site	http://revmo-nadegda.ru/
Communication languages	Russian
Chairman name	Mrs. Nataliya BULGAKOVA
Number of members	10 000
Only Sjögren's association in the country	Yes, only Sjögren's association
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	All rheumatic diseases
Supports research?	Yes
Newsletter (name, periodicity, paper and/or electronic version)	Newsletter - electronic version
Last updated	Winter 2010

TURKEY RHEUMATIC DISEASES

Name and acronym	Society of Information and Support for Patients with Rheumatic Diseases
First established in	27 April 2006
Address	Ankara Turkey
e-mail address	info@romaturka.org
Phone	+90 312 425 7558
Fax	+90 312 419 8409
Web site	www.romaturka.org
Communication languages	Turkish
Chairman name	Başak TARHAN, Başak SONMEZ
Number of members	21 permanent members
Only Sjögren's association in the country	Yes
Dedicated exclusively to Sjögren's or also dedicated to other rheumatic diseases	Also dedicated to other rheumatic diseases
Supports research?	-
Newsletter (name, periodicity, paper and/or electronic version)	-
Last updated	Summer 2009