operations., Consultant for: The author has been provided with consulting fees from AbbVie Canada, Amgen Canada, Eli Lilly Canada, Pfizer/Hospira Canada, Pfizer Global, NovoNordisk, Janssen Canada and Global, Merck Canada, Novartis Canada., N. Robertson Grant/research support from: CAPA receives funding from a number of pharmaceutical companies to conduct its operations., L. Wilhelm Grant/research support from: CAPA receives funding from a number of pharmaceutical companies to conduct its operations., L. Proulx Grant/research support from: CAPA receives funding from a number of pharmaceutical companies to conduct its operations., A. McKinnon Grant/research support from: CAPA receives funding from a number of pharmaceutical companies to conduct its operations., J. Gunderson Grant/research support from: CAPA receives funding from a number of pharmaceutical companies to conduct its operations., C. Reece Grant/research support from: CAPA receives funding from a number of pharmaceutical companies to conduct its operations., A. Sirois Grant/research support from: CAPA receives funding from a number of pharmaceutical companies to conduct its operations.

DOI: 10.1136/annrheumdis-2018-eular.3955

PARE0006 A SUMMARY OF KEY FINDINGS FROM THE SJÖGREN'S SYNDROME FOUNDATION'S NATIONAL PATIENT SURVEY RELATED TO TREATMENTS AND MEDICATIONS USED

S. Taylor¹, K.M. Hammi². ¹Sjögren's Syndrome Foundation, Reston, VA; ²Sjögren's Syndrome Foundation, Reston, United States

Background: Sjögren's is a systemic autoimmune disease that affects the entire body. The purpose of this major national patient survey was to gain an understanding from adults who have been diagnosed with Sjögren's about the impact of the disease on their quality of life, including information on the treatments and medications used to manage the disease.

Methods: The Sjögren's Syndrome Foundation (SSF) conducted the *Living with Sjögren's* survey between May 11 and July 11, 2016. Participants were recruited by Harris Poll from a pool of 9,252 active SSF patient members. The survey was conducted among adults aged 18 years or older who reported having been clinically diagnosed with Sjögren's by a physician or other medical professional. The survey asked closed-ended questions about patient experiences with Sjögren's and the impact it has on their quality of life.

Results: There were 3,072 survey responses (33% response rate), 2,963 of which were included in the analyses. Survey respondents were 96% female and 4% male; 32% were aged 60 years or less. On average, respondents reported using 8.8 medications and treatments to help manage their Sjögren's symptoms, with an average of more than four prescription medications and treatments. When comparing patients living with Sjögren's between 0–4 years and 5–9 years, respondents in the latter group reported using slightly more treatments, on average (8.7), compared to those living with Sjögren's for a shorter period (8.2 mean). Nearly all respondents (97%) reported using eye drops, artificial tears, or non-prescription eye ointments. Other medications reportedly used by a majority of respondents include ibuprofen or other anti-inflammatory agents (81%), disease-modifying anti-rheumatic drugs (DMARDs) (67%), over-the-counter or prescription fluoride (67%), and corticosteroids (62%). Notably, patients 60 years and younger were significantly more likely than patients older than 60 years to have used health food supplements or remedies (90% vs. 87%), exercise (88% vs. 83%), and alternative therapies (70% vs. 58%) in attempt to treat their Sjögren's. Nearly all respondents (96%) indicated they wished that additional treatments for Sjögren's were available. Specifically, respondents indicated a need for new treatments for fatigue (63%), brain fog/forgetfulness (53%), sleep problems (51%), joint pain or swelling (48%) and muscle pain (43%).

Conclusions: Patients reported relying on a large number and variety of treatments to manage their Sjögren's as well as the need for new treatment options to treat the various manifestations of the disease. The findings from this survey will help to inform and support future SSF efforts to increase public and professional awareness of Sjögren's and encourage research into new treatments and a cure.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.5535

PARE0007 FAMILY DAY BY THE SWISS LEAGUE AGAINST RHEUMATISM: A NETWORKING EVENT FOR CHILDREN AFFECTED BY JIA AND THEIR FAMILIES

M. Roffler, V. Krafft. *Swiss League Against Rheumatism, Zurich, Switzerland*

Background: In Switzerland 0,7 out of 1'000 children is affected by juvenile idiopathic arthritis (JIA). The incidence of JIA is 11:100'000 (1). The families affected by JIA are spread over three different language regions (the German, French and Italian regions). It is difficult for these families to get in touch with other affected

families since there is no support group for JIA. A support group has never been established due to the uneven distribution in Switzerland.

Objectives: The aim is to offer continuing education for parents of affected children concerning their chronic disease, as well as their dealing with the illness as a family. Furthermore parents and children shall attain the opportunity to exchange information about their experiences and problems with peers in an informal setting.

Methods: The Swiss League Against Rheumatism has established the so-called "Family Day" (German: Familientag) which features a program for affected children/youths and their siblings as well as a separate program for their parents on the same day. In order to enable families from all Swiss language regions to participate in the "Family Day", it takes place separately in German and French in both language regions. Since most Italian speaking families in Switzerland either speak German or French, the "Family Day" is equally open to them. The Swiss League Against Rheumatism collaborates with the task group "Paediatric Rheumatology Switzerland" in order to develop relevant contents. The program for the parents aims at imparting medical therapeutic knowledge about their child's disease. Several additional main topics (e.g. uveitis, developmental paediatrics) are chosen and presented by certified experts. All are made in layman language and explain medical terms thoroughly. The parents additionally get the opportunity for formal and informal exchange within their group. The children and youth program (0–16 yrs.) is dedicated to a specific non-medical topic (e.g. magic tricks). The children are divided into several age-specific subgroups and are assisted by staff from the Swiss League Against Rheumatism. Teenagers (11–16 yrs.) may attend a specialized program during half a day.

The "Family Days" are easily financed by foundation endowments.

Results: From 2011 to 2017 329 families (1157 individuals) participated in the "Family Day", of which 27% were in the French-speaking part of Switzerland. For participating parents this event became essential in order to educate themselves concerning their child's disease and to exchange experiences with other affected families. For most families the "Family Day" has become a fixed event in their yearly calendar. Many families participate on a regular basis for several years.

Conclusions: The "Family Day" has been taking place for 7 years and remains an objective for the future. Demand from parents of affected children continues to be strong and continues to increase. Since support groups have not yet been possible to implement due to demographics, this one-day-event remains a unique resource for affected families.

REFERENCE:

[1] Hofer M. Personal communication. Prof. Dr. med. January 30, 2018.

Disclosure of Interest: None declared

DOI: 10.1136/annrheumdis-2018-eular.6323

PARE0008 SURVEY RESULTS FROM A NATIONWIDE ONLINE AWARENESS CAMPAIGN SUGGEST A CLEAR DIFFERENCE IN TREATMENT AND PERCEPTION OF QUALITY OF HEALTHCARE FOR PATIENTS DIAGNOSED WITH PSORIASIS ARTHRITIS, PSA, VERSUS PATIENTS WITH SYMPTOMS SIMILAR TO PSORIASIS ARTHRITIS I.E. PSORIASIS AND JOINT PAIN

N. Unesi, E.-M. Dufva, L. Håkansson. *Swedish Rheumatism Association, Stockholm, Sweden*

Background: Psoriasis arthritis (PsA) is a chronic inflammatory joint disease closely linked to psoriasis in the skin. The need for increased knowledge of PsA is extensive in both the public and in healthcare in Sweden. For that reason Swedish Rheumatism Association, Swedish Psoriasis Association and health portal company NetDoktor, with support from Novartis, initiated a web-based awareness campaign, which included a survey, in April 2017.

On December 17, approximately 12,500 people, of which about 4,000 with the diagnosis PsA and 8,500 with psoriasis and joint pain, had taken part of the material. Of these, approximately 2,400 people participated fully and provided detailed information on how they view their disease and the care they are offered.

Objectives: Raise awareness and educate about to PsA aimed specifically to people with PsA or with symptoms consistent with the diagnosis – but also relatives, healthcare professionals and the interested public.

Methods: The awareness campaign consisted of five lessons that provided participants with increased knowledge about PsA, and a survey about their experience of healthcare. The survey gave us a foundation to address the deficiencies in healthcare, and in patient needs. The lessons highlighted the following issues: background, causes, symptoms, comorbidity, diagnostics, drug treatment and prognosis.

Results: The average waiting time for a diagnosis among the survey participants was 3,5 years. Every fourth person had waited 5 years or more, and over 10 percent waited more than 10 years for a diagnosis. The survey showed remarkable