

LUPUS EUROPE

CONVENTION 2021

report

LUPUS EUROPE

Convention 2021



a European Lupus Exchange

24 - 26 September | online

10

PRACTICAL SESSIONS

to improve your life with lupus

INDEX

INTRODUCTION

THURSDAY

PRE-CONVENTION PAN meeting

FRIDAY

OPENING session

VACCINATIONS session

WEARABLES session

SATURDAY

LATEST NEWS in Lupus session

DIET session

FATIGUE session

EXERCISE session

APERITIF meet & greet

SUNDAY

GENERAL ASSEMBLY

LUPUS DRUGS session

SOCIAL LIFE session

INTERACTIONS with HEALTHCARE PROFESSIONALS session

INTRODUCTION

Despite being in the midst of yet another challenging year with Covid19, Lupus Europe was able to host its 32nd Annual Convention from September 24th to September 26th. The event was held online; our second online Convention. We chose to see this as an opportunity to both open our Convention to a wider audience and to directly involve our delegates in the selection of topics they would like to see discussed in the Convention and thus the “10 Practical Sessions to Improve your Life with Lupus” was born.

Convention participants this year came from: Germany, Slovenia, Cyprus, the Netherlands, Belgium, Iceland, Lithuania, Denmark, Greece, Poland, Bulgaria, Italy, France, Iceland, Portugal, Spain, Slovakia, Switzerland, Ireland, Israel, Russia, Sweden, Romania, France, Estonia, Finland, Norway, Czech Republic and the UK.

We had 253 registrations this year. A number of participants were directed to the Lupus Europe Facebook page to follow the sessions as they livestreamed. Our Facebook participants were able to raise questions during the sessions and fully participate in the sessions. The Zoom part of the Convention was restricted to Lupus Europe National Member Delegates, Partners and Official Volunteers. Zoom participants were also able to take part in the workshops that took place after each talk; these were not livestreamed.

Most sessions were also transmitted live or uploaded on Lupus Europe’s Facebook Page. The number of views for each of those sessions are at present:

Lupus & Vaccinations	2092 views
Lupus & Wearables	633 views
Latest News in Lupus: a new day dawning?	1198 views
How Key Lupus Drugs Work: What does taking my Medication Regularly Mean	1731 views
Fatigue : What to do about it?	2122 views
Interactions with Healthcare Professionals	691 views
Lupus & Social Life	1302 views

Please note that the summary below is based on notes taken by board members. It should not be taken as a complete and literal abstract of the presenters’ work and might contain simplifications or unintended omissions. Slides used by the presenters are available for members in the restricted section of our website.

PRE-CONVENTION PAN meeting

A Pre-Convention meeting was held with the Lupus Europe Patient Advisory Network (PAN). There was a productive discussion on what the PAN has been up to and what upcoming projects may be. Lupus Europe presented an upcoming swiss army knife survey, aimed at gathering data that hasn't been previously collected through surveys with industry partners or through the Living with Lupus in 2020 survey. This upcoming swiss army knife survey will be a largely patient derived survey of the patient experience; there will be a PAN workshop on next steps on this and on how to move this project forward.

Following discussions with industry partners a new and exciting potential area for patient involvement has become apparent, which is involving patients in the marketing authorisation and licensing of new drugs (HTA). This leads onto a new project for the PAN which is to become skilled in what is HTA and how can we be involved in it. We are committed in getting patients involved throughout the life history of medications. HTA is the final phase of the life cycle of a drug and it is an area we are very keen to get the PAN skilled up in, so they can be a part of the process in this exciting new opportunity for patient involvement too.

OPENING session



Jeanette Andersen, Chair of Lupus Europe, opened the Convention for our Zoom Participants and for our Facebook participants. Jeanette explained how Zoom and Facebook participants could participate fully in sessions and went through the Convention's agenda.

You can still watch the Convention Opening on the Lupus Europe Facebook Page. To watch the Convention opening, go [here](#)

During the Convention opening we also played a video of the wonderful posters our National Members sent to us from around Europe specifically for the Convention. To watch the video of the posters our National Members sent to us, go [here](#)

VACCINATIONS session



LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

10
PRACTICAL SESSIONS
to improve your life with lupus

VACCINATIONS
for people living with lupus
Vaccination against COVID19 is not the only one recommended for people living with lupus. Let's talk about vaccines in this interactive workshop! What vaccinations should people living with lupus get and why?

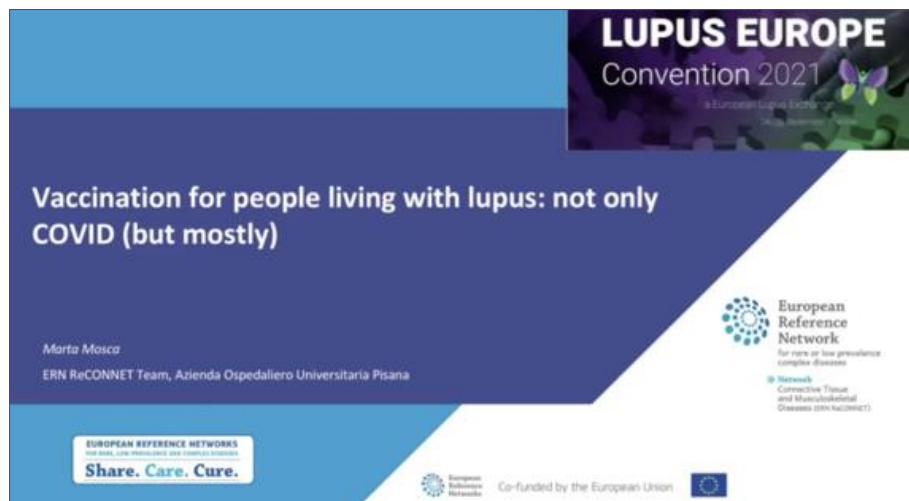
Prof. Marta Mosca

On the 24th of September we had an interactive session with Prof. Marta Mosca, who is a Professor of Rheumatology at the University of Pisa and Head of the Rheumatology Unit at the Azienda Ospedaliera Universitaria Pisana, Italy. At the University of Pisa, Professor Mosca is also the Director of Fellowship Training Program in Rheumatology. Since December 2016 she has been the Coordinator of the European Reference Network on Rare and Hereditary Connective and Musculoskeletal Diseases (ERN ReCONNET).



Prof Mosca's session was on vaccinations for lupus patients. Prof. Mosca talked us through how important it is for lupus patients to be vaccinated against a number of conditions such as flu, pneumococcus, meningococcus and HPV. People should discuss what vaccines they need to have with their medical teams and remember never to get live vaccines if you are immunosuppressed. Prof. Mosca explained that although antibody response may be reduced in patients on certain therapies, such as those on high dose steroids or rituximab, studies have found no increased incidence of adverse events and no increased incidence of flares in lupus patients after vaccination.

Prof. Mosca then went on to discuss vaccines against COVID19 and peoples' hesitancy about them because they were developed so quickly. Prof. Mosca told us that the development of vaccines against COVID19 was so quick because scientists and researchers worked together and that no corners were cut in the medical research; the only thing that was cut was bureaucracy.



HIGHLIGHTS

of this session include

- The recommendation is that all patients on immunosuppressant treatment should have a third vaccination against COVID19
- ERN ReCONNET is gathering evidence from researchers and doctors around Europe on the efficacy of COVID19 vaccinations in people with lupus
- ERN ReCONNET is working with Lupus Europe on guidelines for lupus patients and vaccinations

to WATCH

the session and Q&A

You can still watch this session

on the Lupus Europe Facebook page [here](#)

and also on the LE YouTube Channel **fully subtitled** [here](#)

WEARABLES session



LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

10
PRACTICAL SESSIONS
to improve your life with lupus

WEARABLES
Fitbit, Apple watch, smartphones...
so many measuring devices
that accompany us every day.
Can they help us, lupus patients,
live better with the disease?

Dr. William Dixon

On the 24th of September we had a presentation by Prof. Will Dixon on lupus and wearables. Prof. Will Dixon qualified from Guy's and St. Thomas' Hospitals, London, trained as a rheumatologist in Manchester, UK and has higher degrees from The University of Manchester and McGill University, Montreal. He is a Professor of Digital Epidemiology, Director of the Centre for Epidemiology Versus Arthritis at the University of Manchester and an honorary consultant rheumatologist at Salford Royal NHS Foundation Trust.



His passion is using technology to support clinical care and research to improve patients' lives. This includes the collection and sharing of research quality data from clinicians, collecting patient-generated data including its integration into electronic health records, and analysis of social media data. Recent digital health studies include the national smartphone study and citizen science experiment *Cloudy with a Chance of Pain*, remote monitoring of rheumatoid arthritis (*REMORA*) which uniquely integrates patient-generated data into the NHS, and *Assembling the Data Jigsaw*, a local data integration pilot to use a range of data sources from clinicians and patients in Salford for addressing clinically important questions about arthritis.

Before the session began, we ran a small poll with very interesting results. Over 71% of the attendees at the session either currently have or have used a wearable in the past. Fitbits and other smart watches were popular, with 29% using them; 29% of people had also used apps on smart phones to track various data. When asked if using a device to monitor themselves was beneficial, a resounding 71% say a loud 'YES'.

Prof. Dixon's presentation started with a situation many of us recognised! A woman comes to her usual consultation but struggles to find a parking space. By the time she is in the consulting room, she is stressed and when the consultant asks her 'How have you been over the last 6 months?', she replies 'Fine'. However, when they look at the data on her wearable, it is easy to see a spike in symptoms and together they were able to identify a period of time where her condition was worse than – due to the stress of the morning – she had forgotten about. So, with wearable use we have the ability to capture metrics over time that might be otherwise forgotten and we can use the data to have a discussion with our medical team about any changes in symptoms, any flares and to spot longer-term trends. This may be especially relevant with a fluctuating condition and hard-to-describe symptoms that vary between individuals; the day-to-day state of lupus can be hard to remember – especially in the often stressful and time-pressured environment of a consultation.

Prof. Dixon said there is a growing trend to move towards 'Digitally-enhanced outpatient care' in the UK, with the use of remote apps, remote monitoring and virtual care.



The slide features a header with four logos: 'CENTRE FOR EPIDEMIOLOGY VERSUS ARTHRITIS' (green and black), 'MANCHESTER 1824 The University of Manchester' (purple), 'REMORA' (orange fish), and 'Salford Royal NHS Foundation Trust' (blue) with a small video inset of a woman. The main title 'Symptom tracking integrated into clinical care' is in large black font. Below it, the presenter's name 'Will Dixon' is shown, followed by his titles: 'Professor of Digital Epidemiology', 'Director, Centre for Epidemiology Versus Arthritis &', and 'Honorary Consultant Rheumatologist, Salford Royal Foundation Trust'.

CENTRE FOR EPIDEMIOLOGY VERSUS ARTHRITIS

MANCHESTER 1824
The University of Manchester

REMORA

Salford Royal NHS Foundation Trust

Symptom tracking integrated into clinical care

Will Dixon
Professor of Digital Epidemiology

Director, Centre for Epidemiology Versus Arthritis &
Honorary Consultant Rheumatologist, Salford Royal Foundation Trust

HIGHLIGHTS

of this session include

- The REMORA study's method of using questions sent to an app on patients' phones is useful for capturing fluctuating symptoms that may otherwise be forgotten
- The REMORA study is about to start a phase III clinical trial of an app to investigate whether it can have observable benefits to patients' quality of life and medical consultations
- Patients recall of symptoms between consultations may be affected by many factors
- Most of the wearables currently available were developed to track fitness activity and not a chronic health condition. They may be useful, but development of the next generation of wearables will need patients to be involved

to WATCH

the session and Q&A

You can still watch this session

on the Lupus Europe Facebook page [here](#)

and also on the LE YouTube Channel **fully subtitled** [here](#)

LATEST NEWS in Lupus session



On Saturday morning, September 25th, we had an interactive session and Q&A with Prof. van Vollenhoven on Latest News in Lupus. Prof. Ronald F. van Vollenhoven is Chair of the Department of Rheumatology and Clinical Immunology at the Amsterdam UMC, Director of the Amsterdam Rheumatology and immunology Center ARC in Amsterdam, and Chair of the Rheumatology Research Council at Reade in Amsterdam.



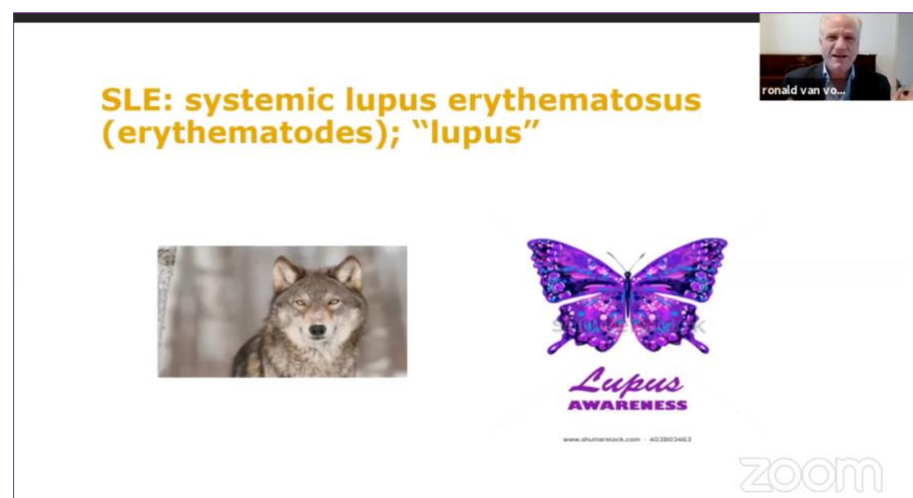
He is the Editor-in-Chief of Lupus Science & Medicine, Member-elect of the EULAR Executive, past-Chair of the Swedish Rheumatology Society Professors' Council, co-founder of the IRBIS registry for biologics in SLE, the CERERRA registries collaboration

and the NORD-STAR collaboration for Nordic trials in the rheumatic diseases, and the initiator of the Treat-to-Target-in-SLE and DORIS initiatives. He is co-author, with Professor Laurent Arnaud, of the Handbook of Systemic Lupus Erythematosus. Professor van Vollenhoven's research interests focus around the development and systematic evaluation of biological and immunomodulatory treatments for rheumatic diseases, including lupus.

Prof. van Vollenhoven's session was very positive; he felt that there might be a new day dawning in terms of lupus treatments. Prof. van Vollenhoven discussed how we can do things better, how we can have better therapies for lupus patients with existing medications or better treatments with new medications.

Prof. van Vollenhoven mentioned that lupus as a disease has two very different animals connected with it, the wolf and the butterfly. He said that this may seem odd because what can be more different than a very dangerous predatory animal (i.e. a wolf) and a very delicate butterfly, but that these two very different animals illustrate how lupus is also very different from one patient to the next, it is a very heterogeneous condition.

Treat-to-target in SLE was also discussed as were a number of existing and new medications as well as potential medications currently in trials.



HIGHLIGHTS

of this session include

- There may be a new day dawning for lupus in terms of treatments, the future looks positive
- Prof. van Vollenhoven is expecting a lot of new therapies and treatments to come along
- There are over 100 genes involved in lupus, there isn't a specific lupus gene
- Lupus is an extremely heterogeneous condition

to WATCH

the session and Q&A

You can still watch this session on the Lupus Europe Facebook page [here](#) and also on the LE YouTube Channel **fully subtitled** [here](#)

DIET session

LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

DIET
and RHEUMATIC DISEASES

Food and diet are so often hot topics on social media...
but what do we truly know about the impact of diet on lupus?
What should we eat or avoid? Join this interactive session to learn about
the science on diet and rheumatic diseases and find out practical suggestions
about eating habits that will help you live better with lupus!

10
PRACTICAL SESSIONS
to improve your life with lupus

Dr. Elena Philippou
& **Dr. Elena Nikiphorou**

On Saturday, 25th of September, we had an interactive session and Q&A on diet and rheumatic diseases. Consultant Rheumatologist, Dr. Elena Nikiphorou, and Clinical Dietician, Dr. Elena Philippou, joined forces specifically for this session and brought to us a presentation on the science of food in rheumatic diseases complete with practical recommendations and tips on diet people could use to make their life with lupus better.



Dr Elena Nikiphorou MBBS/BSc, FRCP, MD(Res), PGCME, FHEA, is a Rheumatology Consultant at King's College Hospital and Adjunct Senior Lecturer at King's College London, in London, UK. She has a clinical and academic interest in inflammatory

arthritis (IA), with much of her research to date focusing on predictors of long-term outcomes of disease and the role of comorbidities. Dr Nikiphorou also has a keen interest in nutrition and inflammation and has published relevant scientific pieces of work, including the first ever educational online module in nutrition for the European Alliance of Associations for Rheumatology (EULAR). She has been involved in several task forces leading to the development of management and other recommendations at European level. She is the first author of the EULAR recommendations for the implementation of self-management strategies in patients with inflammatory arthritis, published earlier this year. Dr Nikiphorou has been the recipient of multiple awards, bursaries and competitive roles, at national and international level and has held various leadership positions over the years, including the presidency of the Rheumatology & Rehabilitation section at The Royal Society of Medicine and the Chair of the largest network of young rheumatologists and researchers in Europe (The Emerging EULAR Network).



Dr Elena Philippou PhD, RD, FHEA is an Associate Professor in Nutrition-Dietetics at the University of Nicosia and a Visiting Lecturer in Nutritional Sciences at King's College London, UK. Dr Philippou's research focuses on diet for prevention of degenerative disease, and more specifically, the effects of the Mediterranean diet and carbohydrate manipulation on cognitive function, cardiometabolic factors and rheumatic disease, aiming to identify dietary factors that can prevent disease and/or improve outcomes. Her research is published in a number of scientific papers in international peer-reviewed journals and she is the editor of a book titled: 'The Glycaemic Index' by CRC Press, USA (2018). She has a number of National and International collaborations including being an active member of the American Congress of Rehabilitation Medicine Neurodegenerative Diseases Networking Group. Dr Philippou also has extensive experience as a registered dietitian and practices advising adults and children on diet-related issues.

Dr. Nikiphorou & Dr. Philippou went into detail on why certain foods or ingredients have influence on a person's immune system. They discussed foods and ingredients that are best to avoid and why it is important that lupus patients avoid those specific foods. Dr. Nikiphorou & Dr. Philippou explained a great deal on food and its potential effect on the immune system from a scientific basis, with information based on studies and a scientific perspective.

They discussed the importance of following an anti-inflammatory diet in rheumatic diseases, including lupus, and highlighted that the easiest way to do this would be through the Mediterranean diet. Very clear examples of different food options that were inflammatory and anti-inflammatory were given, with respect for people's individual circumstances and potentially different access to food. We found out the scientific reasons olive oil is better for inflammation than peanut oil, what we should eat if we are allergic to fish to get omega-3 fatty acids in our diets (walnuts!), that coffee in moderation may be ok for people with lupus and that a bit of dark chocolate and a glass of red wine have scientifically proven benefits against inflammation!

HIGHLIGHTS

of this session include

- Up to three cups of coffee per day may be ok for people with lupus as a general rule
- Following an anti-inflammatory diet can make a big difference in rheumatic diseases, including lupus. The easiest way to do this would be through the Mediterranean diet
- A bit of dark chocolate (75% cocoa) and a glass of red wine a day are anti-inflammatory
- Diet cannot cure lupus

This presentation is not available to watch online anymore at the request of the presenters (for future use)

FATIGUE session

LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

10
PRACTICAL SESSIONS
to improve your life with lupus

FATIGUE
what do do about it?
Fatigue is the most commonly mentioned symptom and the most bothersome for many. Let's talk about it and share practical tips and tricks on how to deal with it

Dr. Natasha Jordan

On Saturday afternoon, the 25th of September we had an interactive workshop on Fatigue with Consultant Rheumatologist Dr. Natasha Jordan. Dr Jordan studied Medicine at University College Dublin followed by higher specialist training in General Internal Medicine and Rheumatology. She subsequently worked for 5 years at the Louise Coote Lupus Unit, St Thomas' Hospital, London. She has been the recipient of an Arthritis Research UK Fellowship and the Graham Hughes Clinical Research Fellowship allowing her to undertake research in the areas of SLE and vasculitis. She obtained her PhD from King's College London investigating the genetics of lupus nephritis. Her major clinical and research interests are autoimmune connective tissue diseases and systemic vasculitis. Dr Jordan has a keen interest in patients with lupus.



Dr. Jordan opened the session with a presentation on fatigue. She explained that fatigue in lupus could be defined as debilitating periods of exhaustion that interfere with normal activity. Dr. Jordan stated that 80-90% of patients with SLE report fatigue to be their most debilitating and profound symptom that negatively impacts their quality of life. She went on to say that 50% of SLE patients report experiencing severe fatigue.

Dr. Jordan explained that fatigue has different features: physical, mental and emotional. She talked about the scientific aspects of fatigue in lupus including how difficult it is to measure fatigue and that at the moment there is no objective, scientific way to measure fatigue which is problematic given that so many people with lupus experience fatigue as their most profound, debilitating symptom.

The session then moved into practical tips & tricks on how to deal with fatigue in lupus. Studies have found that aerobic fitness has a positive impact on fatigue in SLE. However, Dr. Jordan informed us that a lot of lupus patients do not exercise, finding it very difficult to engage or remain engaged with exercise programmes and fearful that exercise will trigger flares. Physicians need to meet patients where they are and to help patients get motivated and stay motivated in terms of exercises. Studies have not found any evidence that physical exercise induces flares in lupus, which is a worry patients often have. Physiotherapy and hydrotherapy may also be very helpful for fatigue in lupus.

Improving quality of sleep can also help fatigue in SLE. To improve quality of sleep it is important to wind down one hour before sleep, reduce caffeine intake, avoid alcohol and take pain killers if in pain. It is also important to adjust the room for optimum sleep conditions, including regulating the temperature, removing disturbances and adjusting the lights. Mobiles and electronic devices should not be kept on bedside tables, we should not have electronics around bedtime as they can disturb our sleep patterns. Reducing stress and anxiety, such as through meditation and mindfulness, may be helpful for fatigue in SLE.

One of the key take-aways of Dr. Jordan's talk is that fatigue in lupus is multifactorial so the management needs to be multifactorial. To improve fatigue doctors have to treat active disease, manage any underlying conditions (i.e. anaemia, hypothyroidism, fibromyalgia, chronic pain et cetera), work with patients to introduce psychosocial interventions to reduce psychological distress and improve coping abilities, improve sleep quality and introduce aerobic exercise programmes (graded exercise).

Fatigue in Lupus What to do about it

Dr Natasha Jordan
Addenbrooke's Hospital, Cambridge

HIGHLIGHTS

of this session include

- Low vitamin D is very prevalent among lupus patients and many be associated with photosensitivity along with chronic use of corticosteroids. It is recommended that lupus patients have a test to measure their vitamin d levels and substitute it if it is found to be low
- Sleep quality can take weeks or months to repair
- Fatigue can improve with aerobic exercise
- Exercise does not cause lupus flares
- Planning is important: make a plan and separate things which you can achieve during the day
- Prioritizing is also key in managing fatigue: List the most important items you have to do in a day. Do only these items today and do the rest tomorrow. Consider delegating some items if possible
- Pacing as a management tool: break down tasks into the achievable chunks. Do not do everything at once. Slow and steady wins the race
- A lot of us don't discuss the impact of fatigue on our day to day lives and functioning with our doctors. It is important to talk about this with our doctors, so they are aware of how it affects us
- Fatigue in lupus is incredibly common, difficult to assess and manage

to **WATCH**
the session and Q&A

You can still watch this session
on the Lupus Europe Facebook page [here](#)
and also on the LE YouTube Channel **fully subtitled** [here](#)

Fatigue in SLE

Fatigue has wide ranging effects on quality of life, resulting in significant disruption to daily function.

Wider implications for work, exercise, and leisure activities

High prevalence of employment disability related to fatigue reported in lupus

Fatigue is associated with impaired concentration, which often has implications on education, in particular in younger patients with lupus.



EXERCISE session



LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

EXERCISE

Should people living with lupus exercise?
What kind of exercise might be beneficial?
What kind of exercise should be avoided?
How can I start if I am not exercising today?
Join this session to find out tips
and tricks on exercise and lupus!

10
PRACTICAL SESSIONS
to improve your life with lupus

ALL of US

Saturday, 25th of September Dr. Tom O'Dwyer gave a presentation on "Exercise and Lupus". In 2016, Dr. O'Dwyer completed his PhD entitled "*Physical activity and Fitness in Ankylosing Spondylitis*" in Trinity College Dublin. Subsequently, Dr. O'Dwyer lectured in the Department of Clinical Therapies in the University of Limerick and began work as a postdoctoral research fellow with the Discipline of Physiotherapy of Trinity College Dublin. Dr. O'Dwyer is a chartered physiotherapist with domestic and international experience working in interdisciplinary teams in acute settings and outpatient clinics. A member of the Irish Society of Chartered Physiotherapists, since 2015 he has been on the committee for the rheumatology clinical interest group.



LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

BIO
Dr Tom O'Dwyer

10 PRACTICAL SESSIONS
to improve your life with lupus



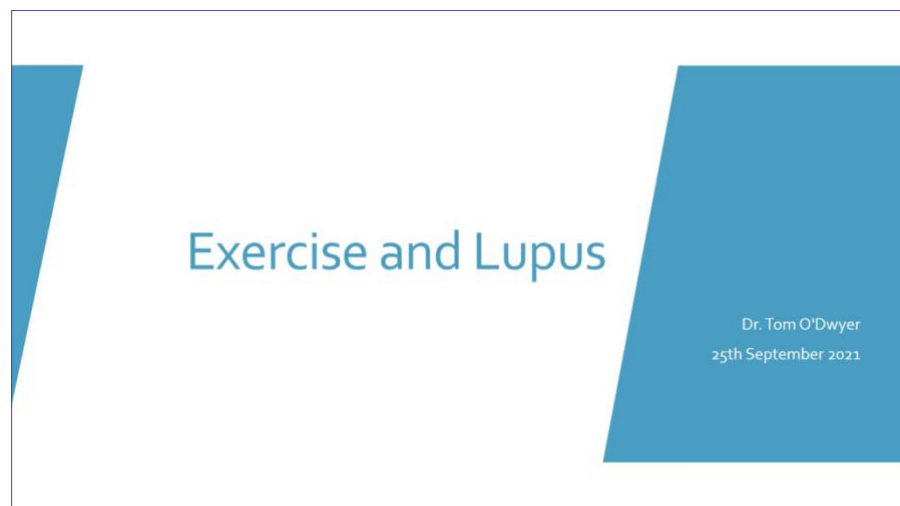
His current research interests are in physical activity, exercise and behaviour change interventions among individuals with musculoskeletal and rheumatic conditions. With a BA Communication Studies from Dublin City University, Dr. O'Dwyer is also interested in using technology to solve contemporary healthcare problems. In his work in the eHealth sector, Dr. O'Dwyer brings a blend of clinical and academic experience to develop and implement care pathways for individuals with chronic conditions.

We all agree that exercise is a good thing, but how do we exercise safely for our lupus? What are the best exercises or activities to take on? How much is enough? How do we get started, and how do we maintain a good exercise habit?

In a quick poll to get things started, we found that 44% of the audience exercise at least 30 minutes each day, and a further 33% at least once or twice a week. Our speaker, Tom O'Dwyer, a physiotherapist by training gave us a little history about exercise and lupus. The first study carried out specifically on lupus and exercise – based on previous work in rheumatic arthritis – was published in 1989, and found that exercise decreased fatigue, improved joint pain and led 70% patients to report 'having more energy!'. Up to this point – only 30 years ago – the advice commonly given was to rest as much as possible, but things have changed a lot since then.

Most lupus advocacy groups agree with this, and there are many videos out there, along with other support, that contain gentle exercises specifically designed to keep lupus patients active. Lupus Europe has developed a complete exercise programme for lupus patients, endorsed by many leading lupologists and approved by EULAR. To find out more, go [here](#)

Dr. O'Dwyer has carried out a literature review on exercise and lupus but found only 10 journal articles relating to this topic. In a paper published in 2017, he found that one problem is that most trials of exercise in lupus focused on physical fitness but did not take into account any cardiovascular risks common in lupus. Although most trials found that exercise was well-tolerated, safe, lowered fatigue and lowered depression, there were side effects such as transient increase in pain, flares of lupus and increased fatigue at the start of a programme. Anyone considering exercise should start by asking a trained professional – perhaps ask your GP or consultant for a referral to a specialised physiotherapist – and work with them for an initial assessment. Together you can then plan a programme that takes into account not just your personal risk factors, such as cardiovascular or joint problems, but also that contains a good range of activities, expert monitoring and flexibility – a programme should alter as you improve or have 'easy sets' for those days when you really need a break!



HIGHLIGHTS

of this session include

- Improvements in weight, joint movement, mental health and confidence – as well as improved cognition! – were not always metrics measured by trials, although often mentioned by patients
- Exercise has been found to increase general mobility, energy levels, reduce steroid side-effects (and can also mean being able to lower steroid use) and even prevent progression of the disease, especially around cardiovascular issues, weight gain and osteoporosis
- The best exercise is whatever you find fun
- Fun + Routine = a sustainable habit
- There are four main areas that exercises should cover – resistance (to improve muscle strength and bone density), aerobic (to improve the health of heart and lungs), flexibility (to keep mobility and balance at a good level) and neuromuscular
- The biggest barrier to exercising regularly is time. Most people do not feel they have time to fit an exercise programme into their daily lives, and with a changeable condition this can be even harder, especially during flares
- Comorbidities might complicate designing a programme and need to be taken into consideration

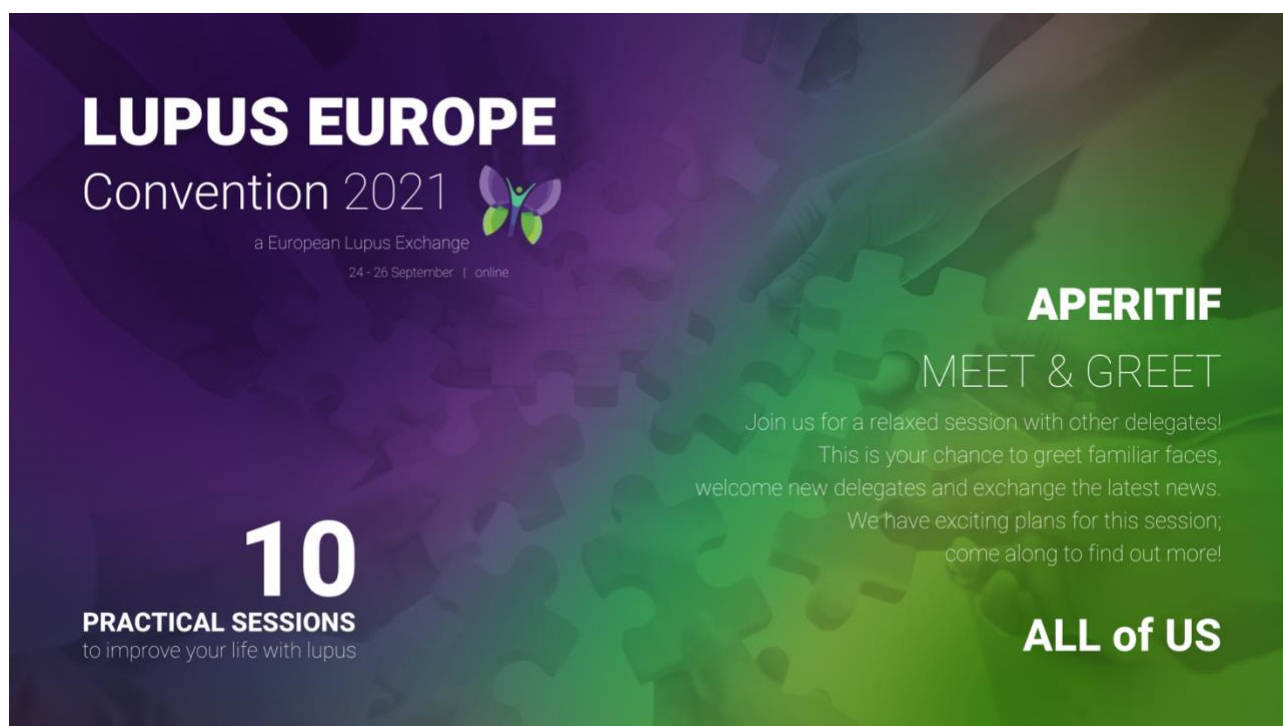
to WATCH

the session and Q&A

You can still watch this session

on the Lupus Europe YouTube Channel **fully subtitled** [here](#)

APERITIF meet & greet



As we conducted our 2021 Convention virtually, we decided to include a virtual “Aperitif” session in our Convention agenda. Usually, our convention would include an element of socialising, whether that be over a coffee at breakfast or a wine at the bar in the evening. We appreciated this would be difficult to recreate in our online platform, so, we decided to dedicate a specific time to this. To break the ice, we asked participants to come along to the session with snacks and a cocktail! We also shared a step-by-step guide on how to make an origami butterfly with participants before the session and asked them to bring a completed origami butterfly to the Aperitif. The aperitif session opened with a fun quiz we all did together! We then broke up into small groups and had the chance to go through a quiz together and get to know each other a bit more. We learned a lot over the session including funny stories about our pets and that we have a master mariner among our members! The session was wonderful, bringing our members a bit closer albeit virtually.

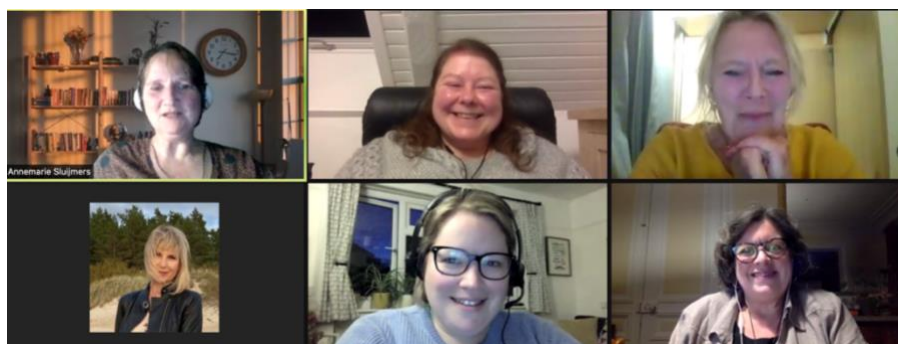
members with their origami Butterflies



GENERAL ASSEMBLY



The General Assembly session was held on Sunday morning, September 25th. The session was only for Lupus Europe National Members. The General Assembly elected Jeanette Andersen, Aldevina Sturiene, Amy Somers and Anne Charlet to the Board of Directors of Lupus Europe. We also welcomed Lupus Russia as an Associate Member.



After a General Assembly on Sunday, September 25th and a Board Meeting on Wednesday, September 29th, we are happy to present you with the new Board of Directors of Lupus Europe: Jeanette Andersen - Chair; Anne Charlet - Vice Chair; Annemarie Sluijmers - Secretary; Elfriede Wijsma - Treasurer; Marisa Costa - Board Member; Amy Somers - Board Member and Aldevina Sturiene - Board Member.

Marisa Costa is absent from the picture above, as she couldn't be with us that evening

LUPUS DRUGS session

LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

**HOW KEY
LUPUS DRUGS WORK**
what does taking
my medication regularly
mean?

Taking a number of medicines for life can be very difficult.
Let's find out how key lupus medications work
and discuss how treatment adherence impacts disease activity
and what we can do to make adherence simpler.

10
PRACTICAL SESSIONS
to improve your life with lupus

Dr. Arvind Kaul

On Sunday, September 26th Consultant Rheumatologist Dr. Arvind Kaul gave a presentation followed by a Q&A session on “How key lupus drugs work: what does taking my medication regularly mean?”. Dr Kaul is head of rheumatology and lupus patient care at St. George’s Hospital, London. He is also Chair of the Trustees at the Graham Hughes International Charity which is dedicated to educating patients, doctors and anyone else affected by antiphospholipid syndrome, a common comorbidity associated with lupus. He has a wide range of experience in general rheumatology, but has a special interest in connective tissue disorders, inflammatory arthritis and lupus having previously worked at the Lupus Unit at St. Thomas’ Hospital in London.

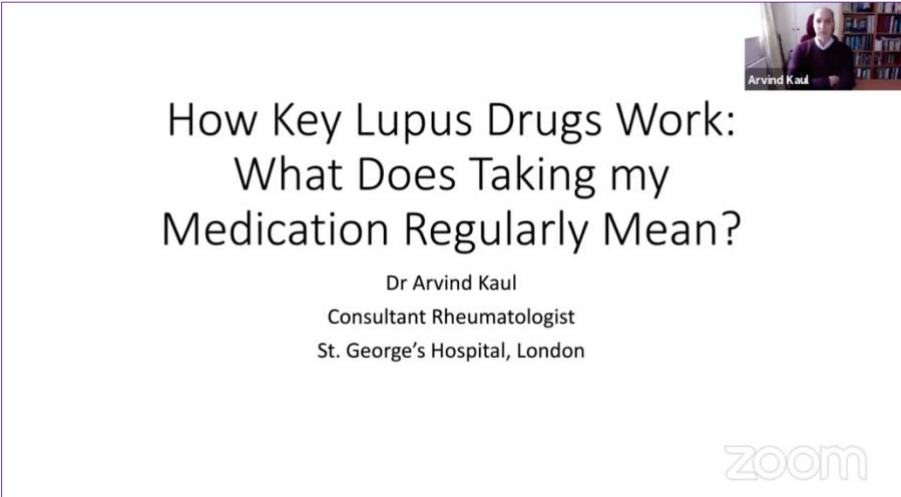


Dr. Kaul opened his presentation by saying that in a perfect world your medication would be the right one for your situation, stage of life, plans for a family, specific type of lupus and general health.

As we all know our world isn't perfect and there are side-effects from all medications that can become a real problem either as short terms issues that may clear up if the drugs are stopped to side-effects that can lead to serious complications in the short or possibly even in the long term. These side effects can cause complications in daily life – nausea that may mean not being able to take the children to school or skin lesions that require constant applications of lotions for example. Good prescribing is a constant balance between the benefits of the medications in the sort and long term against any harms that might be caused in the long term and the problems taking the drug may present in daily life.

Lupus is a very complex, heterogeneous condition and it is very hard to create medications that are specific to each person's experience and complications of lupus. Prescribing drugs for lupus is a delicate art as much as a science. The ideal is to 'control early and reduce quickly', with the hope that medication can be reduced over time, so a patient only takes a minimum of drugs with the lowest possible side effects and the maximum impact on the condition.

Dr Kaul also talked about the long history of drug development for lupus from the early days of 'steroids for all' to the current exciting situation of many new drugs in development and approaching market. Starting with steroids that suppress immune activity, we now have drugs that focus on specific areas of the immune system – reducing B cells, stopping signaling chemicals such as interferons or slowing the production of antibodies. All have good points but also side effects.



The image is a screenshot of a Zoom video conference. In the top right corner, there is a small video feed of Dr. Arvind Kaul, a man with glasses and a beard, wearing a dark sweater. The main part of the screen displays a presentation slide with a white background and a purple border. The slide title is "How Key Lupus Drugs Work: What Does Taking my Medication Regularly Mean?". Below the title, the speaker's name and affiliation are listed: "Dr Arvind Kaul, Consultant Rheumatologist, St. George's Hospital, London". The Zoom logo is visible in the bottom right corner of the slide.

How Key Lupus Drugs Work: What Does Taking my Medication Regularly Mean?

Dr Arvind Kaul
Consultant Rheumatologist
St. George's Hospital, London

zoom

HIGHLIGHTS

of this session include

- The future of drug treatment for lupus is to catch it early, treat it hard if necessary and then reduce drugs to a minimum tailored to the individual
- In the future the hope is that genetic testing may be used in people referred for high antibody levels in routine blood tests, to see if they might go on to develop lupus and treat them even quicker if they do
- There is a vast array of available medications that may be used to treat lupus with lots more medications in the horizon

to WATCH

the session and Q&A

You can still watch this session

on the Lupus Europe Facebook page [here](#)

and also on the LE YouTube Channel **fully subtitled** [here](#)

SOCIAL LIFE session



LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

10
PRACTICAL SESSIONS
to improve your life with lupus

Lupus and SOCIAL LIFE
Let's talk about work and family life!
How can people with lupus balance their health and their social life?
What recommendations, tips or tricks can we use?
What issues or solutions can you share with others!

Rebecca Gilman

On Sunday afternoon 26th of September, Lupus Research Clinical Nurse Specialist Rebecca Gilman talked to us about Lupus & Social Life. Rebecca Gilman is a Lupus Research Clinical Nurse Specialist at the University of Birmingham. She is active at the Birmingham City Hospital Lupus Unit, which has been a Lupus UK Centre of Excellence since 2005 and is headed up by Professor Caroline Gordon. She works closely with Lupus UK on various projects, most recently on addressing issues obtaining hydroxychloroquine tablets for lupus patients and she works very closely with lupus patients in her clinical practice.



Rebecca opened her presentation by going over the spoon theory, created by lupus patient Christine Miserandino. She stated her aim is for patients to be able to make

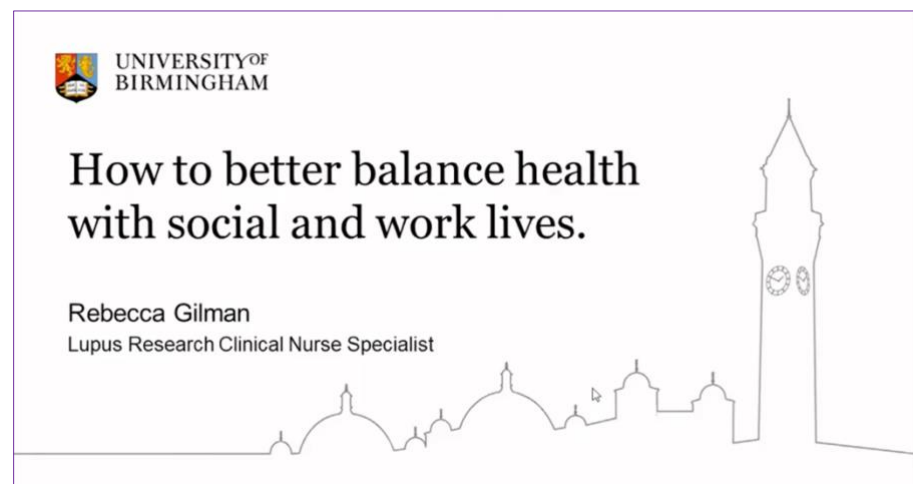
informed decisions about their condition. Fatigue is a very common symptom for lupus patients and certainly included in the questions people most commonly ask her. Rebecca said that fatigue is an invisible symptom, but it can have a profound impact on patients' lives: prioritisation and planning are very important to manage fatigue.

Everyone has natural energy cycles; we all have peaks and troughs of energy at certain points through the day. Some days can be full of energy for everyone, others can be energy – empty. It is very important to map these energy cycles and changes in our energy levels to be able to better manage fatigue and our lupus.

Sometimes lupus patients end up not pursuing certain careers or dreams they may have had because of their disease. Sometimes it can seem like everything has been turned upside down because of lupus. People with lupus can grieve for the person they wanted to become and that is ok. As lupus patients we often need support from our family and friends. Not everyone can give us support and that's ok, but it's good to have a small support network or cycle of people you can lean on.

As part of planning and prioritization we need to learn how to refuse some activities and decline invitations sometimes. It is important for us to be flexible with ourselves. Social media sets high expectations; we must realise that what is presented in social media can be very different to reality.

It can be hard to find a job with a fluctuating condition like lupus, but it is possible. There are a lot of possible careers people can have, but there are also people with lupus who don't work. The best time to start a new career is when your lupus is stable. Not everyone at work can understand the impact of a fluctuating condition, but we do not need everyone to know; we just need few key individuals who can offer support. Rebecca advises a careful, quiet and private conversation with a manager at work, approached in a professional way. Rebecca discussed possible solutions for work issues in lupus patients for instance – changing work hours slightly, having longer lunch breaks, possibly having a break to take a nap if needed, or maybe have 3 shorter breaks, or a quiet space. Referring a manager to a patient organisation can be helpful in those instances as can sharing a letter from a doctor that explains the condition and its impact.



HIGHLIGHTS

of this session include

- People with SLE may be afraid to engage in new relationships and may try to hide the condition from any new romantic partner
- It is important to map our natural energy cycles as part of better managing fatigue and our lupus
- 25 years ago, lupus patients were told not to have children, but now they can have children and pregnancy can go quite well with no bigger complications, provided it's planned and the condition is stable
- A lupus diagnosis doesn't change who we are

to WATCH

the session and Q&A

You can still watch this session

on the Lupus Europe Facebook page [here](#)

and also on the LE YouTube Channel **fully subtitled** [here](#)

INTERACTIONS with HEALTHCARE PROFESSIONALS session

LUPUS EUROPE
Convention 2021 
a European Lupus Exchange
24 - 26 September | online

**INTERACTIONS
with HEALTHCARE
PROFESSIONALS**

Is there a patient-doctor communication gap?
How can people living with lupus
be better prepared for consultations?
How can we improve communication
between patients and medical professionals?
How can we set common treatment goals with our medical team?
How can we make sure the questions we have in our mind – but
never dared to ask – are properly raised and answered by our doctor?

Join this session for a fascinating discussion
and to learn practical tips and tricks
on improving communication!

10
PRACTICAL SESSIONS
to improve your life with lupus

Dr. Chiara Tani

On the afternoon of Sunday 26th of September Prof. Chiara Tani held an interactive session on “Interactions with Healthcare Professionals”. Professor Chiara Tani is a rheumatologist working in the Rheumatology Unit, Pisa University Hospital, Italy. Her long-term research experience is focused on SLE and connective tissue diseases; specific fields of interest are patients reported outcomes, long-term outcomes and pregnancy in lupus. She has a long-term clinical experience on systemic autoimmune diseases, together with Prof Marta Mosca she is the founder of the Pisa Lupus Clinic in Pisa and currently in charge of the pregnancy clinic.

Prof. Tani explained to us that according to research and patient feedback there is a communication gap between physicians and patients and that the views of the patients on communication are often very different from the views of physicians. Physicians are often focused on blood work and disease markers and patients are often focused on function and quality of life. Physicians may be under time constraints during appointments and patients may forget issues they experienced during the time (usually months) that passed since their last consultation. Prof. Tani gave a number of practical tips & tricks on how best to communicate with doctors and how to prepare for medical appointments, such as taking a notebook with us so we can take notes during the consultation and having a list of questions to ask the doctor that you can read from during the appointment.

INTEGRATE (INTEGRATING patient reported outcomes, clinical data and quality indicators to physician drive data in clinical management of chronic rheumatic diseases: the paradigm of Systemic Lupus Erythematosus) is a project that has been created to research patient/doctor communication with the aim of getting better outcomes for lupus patients and merging these differing views of patients and doctors in lupus care. Prof. Tani gave us an update on the INTEGRATE project.



HIGHLIGHTS

of this session include

- There is a known communication gap between patients and doctors
- Patients may be focused on function and quality of life and physicians may be focused on blood work and disease activity
- There are lots of practical steps to take to bridge the communication gap
- Make a list of questions that you want to ask your doctor and take the list with you to your consultation; you can use that list as a prompt and reminder during your appointment
- Take a notebook with you to your medical consultations to take down notes of any important points during the appointment
- INTEGRATING patient reported outcomes, clinical data and quality indicators to physician drive data in clinical management of chronic rheumatic diseases: the paradigm of Systemic Lupus Erythematosus or INTEGRATE is an ongoing project

to WATCH

the session and Q&A

You can still watch this session

on the Lupus Europe Facebook page [here](#)

and also on the LE YouTube Channel **fully subtitled** [here](#)