From today’s reality, to tomorrow’s ‘Vision for Lupus’

This event has been organised and funded by GSK

IFEMA Feria de Madrid
08:15 – 09:45
14 June 2019
Welcome and introductions
Timings

- Today’s symposium will run for an **hour and a half**
  - Welcome and presentation (65 minutes);
  - Interactive panel discussion (25 minutes)

Audience interaction

- Please submit questions via **Slido** throughout the symposium
  - To be addressed during the panel discussion session at the end
- Questions will be posed to the audience throughout this symposium:
  - Respond to questions via Slido

Feedback

- Please complete the **evaluation forms** on your seats and hand them to a GSK representative on the way out

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Please kindly ensure all mobile phones are on **silent**
Go to slido.com and enter the event code: #visionforlupus

Ask questions to be answered during the panel discussion

Share your thoughts and opinion by voting in live polls
Test question

Where are you from?

A. Europe
B. North America
C. South America
D. Asia
E. Australia
F. Africa
<table>
<thead>
<tr>
<th>Time</th>
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</table>
| 08:15 | Welcome and Introduction  
Overview of *A Vision for Lupus* initiative and key findings | Dr Susan Mayor (Moderator)  
Dr Chiara Tani (Chair)  
*Rheumatologist, University of Pisa, Italy* |
| 08:30 | Disease Awareness:  
*What is needed, how and why?* | Dr Patricia Cagnoli  
*Rheumatologist, University of Michigan, US* |
| 08:45 | Integrated Service Delivery:  
The reality and what is possible | Dr Chiara Tani (Chair)  
*Rheumatologist, University of Pisa, Italy* |
| 09:05 | Clinical Research:  
*Preparing for the future together* | Professor Chris Edwards  
*Consultant Rheumatologist,  
University Hospital Southampton, UK* |
| 09:20 | Interactive panel discussion:  
*Your opportunity to engage the panel and share your experience* | Dr Susan Mayor (Moderator) and the  
*Faculty Panel* |
| 09:40 | Closing remarks and call to action:  
*What will you do to drive a change in lupus care?* | Dr Chiara Tani (Chair)  
*Rheumatologist, University of Pisa, Italy* |
Speakers

Dr. Chiara Tani
Rheumatologist,
University of Pisa, Italy

Dr. Patricia Cagnoli
Rheumatologist,
University of Michigan, US

Prof. Chris Edwards
Rheumatologist,
University of Southampton, UK

Disclaimers: Chris Edwards = Honoraria, advisory boards, speakers bureau, research support from; Abbvie, BMS, Biogen, Celgene, Fresenius, Gilead, GSK, Janssen, Lilly, Mundipharma, Pfizer, MSD, Novartis, Roche, Samsung, Sanofi, UCB. Patricia Cagnoli = present and past as PI in clinical trials sponsored by BMS, Janssen , Gilead, Lilly, Celgene, AbbVie, GSK, Genentech. Chiara Tani = consultation fees from GSK Italia
A Vision for Lupus

Overview of the initiative and key findings

Dr Chiara Tani (Chair), Rheumatologist, University of Pisa, Italy
The Vision for Lupus Steering Committee

In March 2018, GSK convened a Global Multidisciplinary Steering Committee of lupus experts to discuss the future of lupus research and therapy. The committee included experts from various disciplines and countries, as well as patient advocates and industry representatives.

Prof. David D'Cruz, Consultant Rheumatologist, Guy's and St Thomas' Hospital, UK
Alain Cornet, General Secretary, Lupus Europe
Dr. Patricia Cagnoli, Rheumatologist, University of Michigan, US
Neil Betteridge, Patient Engagement Expert
Dr. Chiara Tani, Rheumatologist, University of Pisa, Italy
Duane Peters, Senior Communications Strategist at the Lupus Foundation of America Inc. and Staff Coordinator for the World Lupus Federation
Lupus Patient, Anonymous

Consultancy fees received from Eli Lilly, GSK, Human Genome Sciences, Aspreva, Bristol-Myers Squibb, Actelion and Teva. He has also participated in clinical trials sponsored by these companies; ii Consultancy fees received from GSK Italy; iii Consultancy fees received from GSK and Crescendo; iv GSK has provided financial support to the World Lupus Federation, Lupus Foundation of America and Lupus Europe; v Consultancy fees received from Amgen, the Global Alliance for Patient Access, Grunenthal, Heart Valve Voice, Lilly, Pfizer, Roche, Sanofi Genzyme, Sanofi Regeneron.

14 June 2019 GSK conceived, developed and led the “A Vision for Lupus” report in collaboration with a Global Steering Committee who received a fee for their services.
The Vision for Lupus mission

The Vision for Lupus Steering Committee’s mission was to:

- Consider current gaps and inconsistencies in care for people with lupus
- Develop patient-centred calls to action to improve the quality of care
- Outline how implementing these calls to action could make a difference to people with lupus

What are the current gaps and inconsistencies in lupus care?

What do we want lupus care to look like in the future?

And, how do we get there?

14 June 2019
## The Vision for Lupus: gaps and inconsistencies in care and calls to action

### Where are the gaps and inconsistencies? | What are the calls to action?
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**Awareness of lupus** | • **Raise awareness of lupus amongst key audiences** including the general public, people with lupus, their families, carers and primary care doctors

**Integrated service delivery** | • **Improve access to specialist and multidisciplinary lupus clinics** to ensure people with lupus are receiving quality care that addresses all aspects of this complex, multisystem disease

**Clinical research** | • **Encourage people with lupus to consider participating in clinical research**, raise awareness of ongoing clinical trials and facilitate access to clinical trial research enabling people with lupus to make autonomous decisions in the management of their condition
1. Question to the audience

What do you think are the biggest barriers to quality lupus care?

A. Lack of awareness amongst the public and healthcare professionals
B. Misinformation online about how to identify / manage lupus
C. Multidisciplinary aspects of lupus care are not ‘joined-up’
D. Limited access to emotional, psychological and social support
E. Barriers to participation in clinical research
Disease Awareness

What is needed, how and why?

Dr Patricia Cagnoli, Rheumatologist, University of Michigan, US
Disease awareness: Gaps and inconsistencies

General public often unaware of lupus and its complications¹

Patients and families often unsure what to expect, and online misinformation may contribute to misunderstandings⁴

Healthcare professionals have short consultation times, lack of disease recognition and out-of-date information⁵

Invisible symptoms and disease fluctuations may lead to lack of empathy for patients and affect mental wellbeing²,³

Poor adherence, treatment failure and adverse events⁵

70% initially misdiagnosed⁶ and diagnosis delays of up to 3.5 years⁷,⁸

Disease awareness: 
Calls to action from the Vision for Lupus report

Raise awareness of lupus amongst key audiences

**Short-term calls to action**
- Cultivate a **group of public figures and/or celebrities** to talk about lupus (i.e. Julian Lennon)
- **Develop a seal of approval** for websites
- **Encourage positive interaction** between people with lupus
- **Disseminate information** to primary care doctors

**Long-term calls to action**
- **Train patient advocates** to provide accurate information on lupus
- **Improve education** around the psychological manifestations of lupus
2. Question to the audience

As a healthcare professional, how do you like to receive ongoing professional education and training?

A. Education through journals, i.e. produced by organisations like the Royal College of GPs in the UK
B. Training courses / events provided at specialist centres
C. Informal small group discussions
D. Symposia events
E. Online education, i.e. IME courses
F. Learning directly from colleagues
3. Question to the audience

Which areas of lupus care do you think are most lacking in terms of patient education?

A. What is a ‘flare’ / a symptom of lupus and what is not - when it is time to see a doctor?

B. Planning emotional, psychological, social aspects of life with lupus

C. Importance of nutrition, diet and physical activity

D. Managing lupus in pregnancy
### Initiatives making a difference to disease awareness

**How are the recommendations in the report currently being addressed?**

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<th>Healthcare professionals</th>
<th>Patients</th>
<th>Industry</th>
<th>Advocacy groups</th>
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<tbody>
<tr>
<td>▪ British Society of Rheumatologists Fellowship¹</td>
<td>▪ Lupus UK educational materials</td>
<td>▪ IME Medscape⁶ and EULAR Lupus Academy⁷</td>
<td>▪ Lupus Foundation of America:</td>
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<td>▪ SLEEUNO Training Bursary Programme</td>
<td>▪ Lupus Foundation of America:</td>
<td>▪ TALKSLE⁸ (industry-funded)</td>
<td>▪ ‘Advocate with us’¹⁰</td>
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<td>▪ EULAR-endorsed course for young rheumatologists</td>
<td>▪ ‘Could it be lupus?’ campaign¹²</td>
<td>▪ ‘Us In Lupus’ website ⁹</td>
<td>▪ Julian Lennon and Lucy’s legacy¹¹</td>
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<td>▪ Sessions dedicated to lupus for nurses at Lupus clinic Pisa</td>
<td>▪ ‘Be Fierce and Take Control’ website³</td>
<td>▪ Continued partnership with patient advocacy groups</td>
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<td>▪ Internal grand-round sessions with other specialists at Lupus Clinic Pisa</td>
<td>▪ ERN- ReCONNET website⁴</td>
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<td>▪ Pregnancy, diet, physical activity brochures in waiting room</td>
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<td>▪ Lupus Europe:</td>
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<td>▪ LFA-REAL system⁵</td>
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<td>▪ Patient Panels initiative¹²</td>
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Example initiatives

How are the recommendations in the report currently being addressed?

How can you leverage resources available to help educate your patients and the community?

Is there a local celebrity with lupus who could help increase public awareness?

Could you lead the development of a local patient support group?

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**Lupus Clinic Pisa**
- Patient meetings
- EULAR-endorsed course for rheumatologists
- Internal sessions on SLE for nurses

**ReCONNET**
European Reference Network for Rare and Complex Connective Tissue and Musculoskeletal Diseases¹,²

**Lupus Foundation of America**
Julian Lennon and Lucy’s legacy³

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Integrated Service Delivery

The reality and what is possible

Dr Chiara Tani, Rheumatologist, University of Pisa, Italy
Integrated service delivery: Gaps and inconsistencies

People with lupus require holistic, multidisciplinary care\(^1\) – but these structures are not widespread

Patients may miss out on some aspects of care if this is limited to rheumatologists only\(^2\)

Patients may struggle to describe symptoms or the burden of lupus to HCPs\(^4\) – and may not report flares\(^5\)

Limited access to multidisciplinary, specialist teams\(^2\)

Some areas may be overlooked, e.g., emotional needs, body- and self-image\(^3\)

Few tools allow for improved patient-physician dialogue\(^2\)

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Integrated service delivery: Calls to action from the *Vision for Lupus* report

Improve access to specialist and multidisciplinary lupus clinics

**Short-term calls to action**
- Co-create interactive tools to improve communication
- Develop evaluation tools to assess the burden of lupus from the patient perspective

**Long-term calls to action**
- Improve access to multidisciplinary teams, including medical specialists, nurses, and support services
- Encourage more doctors to pursue rheumatology as a speciality
4. Question to the audience

What do you think is the most important aspect of delivering specialist / multidisciplinary care?

A. Access to a variety of different specialities working together
B. Physicians and specialist nursing staff working together
C. Optimisation of patient-physician communication
D. Development of patient-friendly lupus evaluation tools
E. Utilisation of patient-reported outcomes (PRO) in care
Lupus Clinic in Pisa, Italy

Experiences from specialist lupus centres based in Europe

One of the best-recognised SLE centres in Italy. Formally established in 2011 to provide multi-disciplinary care to people with lupus

The Lupus Clinic team:

- Prof. Marta Mosca (Director)
- 3 consultants rheumatologists
- 1 researcher, 1 PhD student
- 2 dedicated lupus nurses
- Team of rheumatologists covering the whole spectrum of rheumatic diseases (i.e. osteoporosis and fibromyalgia)
- Nutritionist, Biologist, Pharmacist
- Patients association representative

Specialists working together:

- Nephrologist
- Obstetrician
- Allergologist
- Psychiatrist
- Neuologist
- Pneumologist
- Dermatologist
- Cardiologist
- Endocrinologist
Lupus Clinic in Pisa, Italy
Experiences from specialist lupus centres based in Europe

Integrated services:
- Ultrasonography for musculoskeletal diseases
- Capillaroscopy
- DEXA for bone mineral density
- Pregnancy clinic
- Clinical trial office
- Blood collection centre
- Fibromyalgia clinic
- Chronic pain clinic
- Osteoporosis clinic

Clinics / Services:
- Day service
- Outpatients clinic (2-days/week)
- Day Hospital
- In-patients clinic
- (18 beds)
The patient journey at the Lupus Clinic in Pisa

1. Preparing to visit:
   - Perform lab exams as prescribed during previous visit
   - Fill in patient diary where applicable

2. In the waiting room:
   - First contact with clinic nurse
   - Consent: privacy and data handling
   - Fill in questionnaires on PROs
   - Enrolment in clinical research studies

3. During the visit:
   - Doctor-driven clinical assessment
   - Review PROs and discuss main points
   - Discuss treatment, drug toxicity, results, proposed changes
   - Prescriptions

4. After the visit:
   - Further contact with the nurse to agree date for:
     - next appointment,
     - further assessment
     - drug infusions
   - Or inclusion in waiting list for in-patient clinic
Lessons from the Lupus Clinic in Pisa, Italy

Experiences from specialist lupus centres based in Europe

**Ongoing evaluation of processes to identify areas for improvement**

- Reduce waiting times
- Promote seamless care from GPs to the Lupus clinic
- Optimise consultation time
- Promote early referral from non-specialist clinics
- Digitise clinical charts
- Improve nurse training
- Plans for the future

Promote seamless care from GPs to the Lupus clinic
The Louise Coote Unit (Guys’ and St. Thomas’ Hospital, London) is a centre of excellence dedicated to delivering high quality lupus care:

- Founded in 1986 by Prof. Graham Hughes
- Named after Louise Coote, who died from SLE
- National territory referral unit for patients with APS, SLE, vasculitis
Lessons from the Michigan Lupus Program, USA

Experiences from specialist lupus centres based in the US

- Provides “state of the art” multidisciplinary care
  
  Team of rheumatologists, nephrologists, pulmonologists, haematologists, dermatologists, and high risk obstetricians and gynaecologists

- Comprehensive patient care environment allows us to make expeditious appointments with other specialist physicians, assist in coordinating medical testing

- Researchers are heavily involved in basic research and clinical trials

- Program proudly serves as a resource for the training of physicians and medical students to better serve our community
Specialist and multidisciplinary lupus care initiatives

How are the recommendations in the report currently being addressed?

How can you help to ensure patients at your centre receive quality care for all aspects of their multi-faceted condition?

What could you do to support improved communication between physicians and patients at your centre?

Lupus Clinic Pisa

Experiences from a specialist lupus clinic in Italy

Louise Coote Unit

A day in the life of the Louise Coote Unit - video

Michigan Lupus Program

Experiences from a specialist lupus clinic in the US
Clinical research

Preparing for the future together

Professor Chris Edwards, Consultant Rheumatologist, University Hospital Southampton, UK
Clinical research: Gaps and inconsistencies

There are various barriers to clinical trial participation, often related to logistics, misinformation and lack of encouragement\(^1\)

In particular, conducting clinical research in lupus requires a large pool of patients / trials to be run on an international scale\(^2\)

This can lead to hurdles and significant delays in developing potential new therapeutic options for managing lupus

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2. Comment from Vision for Lupus Steering Committee
Clinical research: Calls to action from the Vision for Lupus report

Encourage people with lupus to consider participating in clinical research – raise awareness and facilitate access

Short-term calls to action

Share information about clinical research with patients at lupus centres

Educate primary care physicians about the importance of clinical research

Make it easier for patients to participate in clinical trials

Long-term calls to action

Involve patients in the design of clinical trials

Help patients become accountable for their own care

Explore other non-pharmacologic clinical trial research
What do you think is the biggest barrier to patient participation in clinical trials for lupus?

A. Lack of information about available trials
B. Physicians do not refer patients
C. Too much complex information to digest before deciding to participate
D. Fear of randomisation to placebo
E. Patient misconception that being a study patient means being a guinea pig
Initiatives making a difference in clinical research

How are the recommendations in the report currently being addressed?


Healthcare professionals

- Ideally, physicians recruit from their own pool of patients – patients trust their own doctors
- Seeking permission to collect data and ask about future trials – from all patients
- Support clinicians to find information about local trials / projects

Clinical trial centres

- Seeing study patients outside of clinic hours
- In the UK:
  - Connective tissue disease networks provide regional trial triage point
  - Network of NHS-funded research facilities

Industry

- Involving patients in trial development
- Improving clinical trial experience for patients
- Providing patient-friendly materials explaining clinical trials
- Sharing study results in plain language summaries
- Supporting the Lupus Research Alliance

Advocacy groups

- Lupus Research Alliance Grant funding for researchers, clinical trial posting, patients information about RCTs
- Clinical trial listings at Lupus Foundation of America
- Outreach to ensure diversity in clinical trials

14 June 2019
Example initiatives

**How are the recommendations in the report currently being addressed?**

*What can you do to encourage your patients to participate in clinical trials?*

*NHS England-committeeed connective tissue disease networks provide regional trial triage point*

*How can we ensure that clinical trials are relevant to patients with lupus?*

*GSK committed to providing study results in plain language summaries*

*Do all your patients receive and understand the results of research they have participated in?*

*Grant funding for researchers, clinical trial posting, and patient information about RCTs*

14 June 2019
Interactive panel discussion

Your opportunity to engage the panel and share your experience
Panel session guidance

- During this session the panel will answer questions related to the content of this symposium session, posed by the medical facilitator.

- Questions and comments will also be welcomed from the audience. Please submit questions to be answered by the panel:
  - To submit a question, go to: www.slido.com
  - Enter event code #visionforlupus and click 'join' and then you will be able to submit your question/s
Closing remarks and Call to Action

How will you take what you have learnt today to make our ‘Vision for Lupus’ a reality for your patients?

Download the report & offer your support at:  
www.visionforlupus.org