

1ST INTERNATIONAL AL AMYLOIDOSIS MEETING

FOR PATIENTS AND DOCTORS



July 5-6, 2024
BRUSSELS



ALamyloidosismeeting.com

PROGRAM

ORGANIZED BY:



**AMYLOIDOSIS
ALLIANCE**
THE VOICE OF PATIENTS

WITH THE COLLABORATION OF:



**1ST INTERNATIONAL
AL AMYLOIDOSIS
MEETING**
FOR PATIENTS AND DOCTORS

July 5-6, 2024
BRUSSELS



JOIN US IN BRUSSELS!

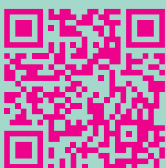
The Amyloidosis Alliance is pleased to welcome you to the first International AL Amyloidosis Meeting, which will be held in Brussels on July 5-6, 2024.

This two-day program will be an extraordinary opportunity to gain insights into all aspects of AL amyloidosis, with a special focus on managing complications linked to organ involvement. It will also provide occasions for patients and medical doctors to learn from each other's experiences.

On the first day, there will be sessions dedicated to patients, and separate sessions for doctors. The second day will feature joint sessions for both groups.

We hope to meet you in Brussels and wish you an inspiring congress!

Agnès FARRUGIA, Frank BRIDOUX and Nathalie MEULEMAN
On behalf of the organizing committee



REGISTRATION AND INFORMATION:
ALamyloidosismeeting.com



ORGANIZING COMMITTEE

- **Prof. Nathalie MEULEMAN**
Institut Jules Bordet (HUB),
Brussels, Belgium
- **Prof. Frank BRIDOUX**
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- **Jean-Christophe FIDALGO**
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- **Prof. Arnaud JACCARD**
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- **Prof. Efstathios KASTRITIS**
National and Kapodistrian
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- **Prof. Olivier LAIREZ**
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Cardiovasculaires,
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- **Barbara MAZZOLINI**
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contre l’Amylose, France
- **Prof. Monique MINNEMA**
Academic Medical Center,
Utrecht, The Netherlands
- **Drs Ben WOLTERING**
Amyloidosis Alliance,
The Netherlands

SCIENTIFIC COMMITTEE

- **Prof. Antoine BONDUE**
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- **Prof. Ute HEGENBART**
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Toulouse, France
- **Dr Nelson LEUNG**
Mayo Clinic, Rochester, USA
- **Barbara MAZZOLINI**
Association Française contre
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- **Prof. Nathalie MEULEMAN**
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- **Prof. Monique MINNEMA**
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Utrecht, The Netherlands
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- **Dr Virginie PASCAL**
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- **Prof. Stefan SCHÖNLAND**
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für Innere Medizin,
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CHU de Limoges, France
- **Prof. Ben SPRANGERS**
Ziekenhuis Oost-Limburg,
Leuven, Belgium
- **Prof. Ashutosh
WECHALEKAR**
Royal Free London Foundation
Trust, Great Britain
- **Drs Ben WOLTERING**
Amyloidosis Alliance,
The Netherlands

**1ST INTERNATIONAL
AL AMYLOIDOSIS
MEETING**
FOR PATIENTS AND DOCTORS



FRIDAY, JULY 5

**DOCTORS
CHANNEL**



08:00 - 08:30 am

REGISTRATION

Welcome coffee | Visit exhibit

08:30 - 09:00 am

INTRODUCTION

Frank Bridoux, Nathalie Meuleman, Stefan Schönland

09:00 - 10:00 am

SESSION 1A

Latest advances in pathophysiology

Chairmen: **Stefano Ricagno (Milano, Italy), Arnaud Jaccard (Limoges, France)**

09:00 Recent insights into the structure and formation of AL amyloid fibrils
Marcus Fändrich (Ulm, Germany)

09:15 Recent insights from in vivo models into AL amyloid fibrils accumulation
and toxicity for organs
Christophe SIRAC (Limoges, France)

09:30 How do fibrils disappear? **Remoted presentation**
Julian Gillmore (London, Great Britain)

09:45 Discussion

10:00 - 11:00 am

SESSION 2A

Supportive care - Part 1

Chairmen: **Nelson Leung (Rochester, USA)**
Michelle Michels (Rotterdam, The Netherlands)

10:00 **Peripheral nervous system**
Michela Bisciglia (Bruxelles, Belgique)

10:20 **GI, nutrition, hypotension, fatigue, muscle loss, sexual dysfunction**
Ornella Rizzo (Brussels, Belgium)

10.40 Round table

11:00 - 11:30 am

Coffee break | Visit exhibit

.../...

11:30 am - 01:00 pm

SESSION 2A
Supportive care - Part 2

Chairmen: Thibaud Damy (Créteil, France), Helen Lachmann (London, GB)

- 11:30 **Cardiac**
Michelle Michels (Rotterdam, The Netherlands)
- 11:50 **Kidney**
Lluís Quintana (Barcelona, Spain)
- 12:10 **Kidney transplantation**
Nelson Leung (Rochester, USA)
- 12.30 **Round table**

01:00 - 02:30 pm Lunch time

02:30 - 03:15 pm

SYMPOSIUM
A multidisciplinary approach to managing systemic light chain (AL) Amyloidosis

Stefan Schönland (Heidelberg, Germany)
Adam Ioannou (London, Great Britain)



03:15 - 04:30 pm

SESSION 3A
How to assess the response to treatment?

*Chairmen: Nathalie Meuleman (Brussels, Belgium)
Monique Minnema (Utrecht, The Netherlands)*

- 03:15 **Biology of the clone**
Stefan Schönland (Heidelberg, Germany)
- 03:35 **Utility of minimal residual disease assessment in AL Amyloidosis**
Ashutosh Wechalekar (London, Great Britain)
- 03:55 **Light chain instability in AL amyloidosis** Remoted presentation
Jeffery Kelly (La Jolia, USA)
- 04.15 **Discussion**

04:30 - 05:00 pm Coffee break | Visit exhibit

05:00 - 06:00 pm

SESSION 4A
Complex clinical cases

*Chairmen: Frank Bridoux (Poitiers, France)
Stefan Schönland (Heidelberg, Germany)*

06:00 pm **END OF THE FIRST DAY**

08:00 pm **DINNER**



**PATIENTS
ASSOCIATIONS
CHANNEL**



FRIDAY, JULY 5

08:30 - 09:00 am

REGISTRATION

09:00 - 09:30 am

INTRODUCTION

Jean-Christophe Fidalgo, president of the Amyloidosis Alliance

09:30 - 11:00 am

SESSION 1B

Diagnosis improvement in 2024

Chairmen: Roland Drewinski (Germany), Olivier Lairez (Toulouse, France)

- 09.30 **Diagnosis: patients journey testimonies**
- 09.45 **How to reduce time to diagnosis in 2024?**
Nathalie Meuleman (Brussels, Belgium)
- 10:05 **How to improve the accurate diagnosis in 2024?**
Christoph Röcken (Kiel, Germany)
- 10:25 **Multidisciplinary approach for improving the diagnosis?**
Olivier Lairez (Toulouse, France)
- 10:45 **Discussion**

11:00 - 11:30 am

Coffee break

11:30 am - 01:00 pm

SESSION 2B

Supportive care of organ involvement

Chairmen: Thibaud Damy (Créteil, France), Helen Lachmann (London, Great Britain)

- 11:30 **Kidney**
Lluis Quintana (Barcelona, Spain)
- 11.45 **Dialysis**
Anne-Lorraine Clause (Brussels, Belgium)
- 12.00 **Peripheral nervous system**
Michela Bisciglia (Bruxelles, Belgique)
- 12.15 **Cardiac**
Christian Knackstedt (Maastricht, The Netherlands)
- 12.30 **Discussion**

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01:00 - 02:30 pm Lunch time

02:30 - 04:00 pm

SESSION 3B

Importance of self-care: physical, mental and emotional wellbeing

Chairmen: **Ric-Paul Hammink** (Amyloidosis Alliance, The Netherlands)
Barbara Mazzolini (Association Française contre l’Amylose, France)

- 02:30 **Complementary treatments: the French experience**
Julie Pompougnac (Créteil, France)
 - 02:45 **Kinesiology / Music therapy**
Audrey Norris, Barbara Mazzolini (Association Française contre l’Amylose, France)
 - 03:00 **Dietetic and environment during and after treatment**
Marianna Arvanitaki (Brussels, Belgium)
 - 03:15 **Physical training during treatment**
Benjamin Depoorter (Brussels, Belgium)
 - 03:30 **Role of patient’s organisation and care givers**
David Gregory (The Ukpata, Great Britain)
 - 03:45 Discussion
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04:00 - 04:30 pm Coffee break

04:30 - 05:15 pm

SESSION 4B

Return to normal life after treatment

Chairmen: **Agnès Farrugia** (Association Française contre l’Amylose, France)
Guy Lippens (Amybel, Belgium)

- 04:30 **Vaccines and prevention**
Ornella Rizzo (Brussels, Belgium)
 - 04:45 **Muscular rehabilitation and sports**
Julien Mathias (Association Française contre l’Amylose, France)
 - 05:00 Discussion
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**PATIENTS
ASSOCIATIONS
CHANNEL**



FRIDAY, JULY 5

.../...

05:15 - 06:15 pm

SESSION 5B

Return to work

Chairmen: *Barbara Mazzolini (Association Française contre l'Amylose, France)*
Ben Woltering (Amyloidosis Alliance, The Netherlands)

05:15 Patients testimonies

05:30 Round table
Return to the same work? How to adapt work and manage fatigue?

With the participation of: Susan Booth (Australian Amyloidosis Network, Australia), Teresa Deutsch (Amyloidosis Support Groups, USA), Julien Mathias (Association Française contre l'Amylose, France), Julie Pompougnac (Créteil, France)

06:15 pm **END OF THE FIRST DAY**

08:00 pm **DINNER**

CONGRESS

DINNER



July 5 - From 8.00 pm

LA BRASSERIE DES ALEXIENS
Rue des Alexiens 63 - Bruxelles

1,9 km from the Hotel nhow (30 minutes walk)
Tram 92 or 93: stop Petit Sablon (travel time: 20 minutes)
Closest metro station: Gare Centrale

**1ST INTERNATIONAL
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FOR PATIENTS AND DOCTORS



SATURDAY, JULY 6

**DOCTORS
& PATIENTS
CHANNEL**



09:00 - 09:15 am

REGISTRATION

Welcome coffee | Visit exhibit

09:15 - 11:00 am

SESSION 6

2024 ISA news

Chairmen:

Bouke Hazenberg (Groningen, The Netherlands)

Stefan Schönland (Heidelberg, Germany)

Ben Woltering (Amyloidosis Alliance, The Netherlands)

- 09:15 Introduction: standards of care in 2024 and current challenges
Arnaud Jaccard (Limoges, France)
- 09:35 Discussion
- 09:45 Latest developments in treatment
Efstathios Kastiris (Athens, Greece)
- 10:05 Discussion
- 10:15 New diagnostic tools and technologies
Hans Nienhuis (Groningen, The Netherlands)
- 10:35 Discussion

11:00 - 11:30 am

Coffee break

11:30 am - 01:00 pm

SESSION 7

Treatment management

**Johnson
& Johnson**

Chairmen:

Barbara Mazzolini (Association Française contre l'Amylose, France)

Nathalie Meuleman (Brussels, Belgium)

- 11:30 The goals of treatment
Paolo Milani (Pavia, Italy)
- 11:50 Potential side effects and how to manage them
Michel Delforge (Leuven, Belgium)
- 12:10 Why and when to stop the treatment
Monique Minnema (Utrecht, The Netherlands)
- 12:30 Discussion

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SATURDAY, JULY 6

**DOCTORS
& PATIENTS
CHANNEL**



.../...

01:00 - 02:15 pm

Lunch time | Visit exhibit

02:15 - 04:00 pm

SESSION 8

Treatments in 2024 and beyond

Chairmen:

Frank Bridoux (Poitiers, France)

Ric-Paul Hammink (Amyloidosis Alliance, The Netherlands)

02:15

Initial patient-tailored treatment strategy

Marie-Christiane Vekemans (Brussels, Belgium)

02:35

Relapse treatment strategy

Ashutosh Wechalekar (London, Great Britain)

02:55

Ongoing clinical trials

Ute Hegenbart (Heidelberg, Germany)

03:15

Position of organ transplantations in 2024

Nelson Leung (Rochester, USA)

03:35

Discussion

04:00 - 04:15 pm

CONCLUSION

Frank Bridoux, Barbara Mazzolini, Nathalie Meuleman,
Stefan Schönland, Ben Woltering

04:15 pm

END OF THE MEETING

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Update 24/06/2024

MDeon Visa Number: 24/V2/15489/009412

GENERAL INFORMATION



VENUE:

nhow Brussels Bloom
Rue Royale 250
B - 1210 Brussels
+32 2 220 66 11
www.nhow-hotels.com

ACCESS:

From the Brussels airport:

- Taxi: 30/40 minutes trip
- Public transport: train to Brussels North Station (15 minutes), then 10 minutes walk or 5 minutes taxi ride to the hotel

From train:

- Brussels North station (850 meters away from the hotel)
- From Brussels-Midi station: 15/20 minutes taxi ride or 25 minutes by metro (line 2)

Public transport:

- Tram 92 and 93: stop Botanique (150 meters away from the hotel)
- Metro line 2 and 6: stop Botanique (150 meters away from the hotel)
www.stib-mivb.be

LANGUAGE:

Official language: English

Translation available (for patients only, in person): English/French

REGISTRATION FEES

	BEFORE 31/05/2024	FROM 01/06/2024
• Doctors	€330	€380
• Paramedical professions	€120	€170
• Fellows / Students *	€100	€150
• Patients / Association's representatives	€30	€50
• Industry	€850	€950
• Streaming (only online)	€125	€175
• Dinner	€70	€70

*On presentation of proof

The registration fees include: attendance to all scientific sessions, congress kit, lunches, coffee breaks.

CANCELLATION POLICY:

Until 10/06/2024: 100% refund with administrative fees of 20 Euros deducted
From 11/06/2024: no refund

ACCOMMODATION HOTEL NHOW:

www.nh-hotels.com
Contact: Alec MIKAILIAN
a.mikailian@nhow-hotels.com | +3222206906

REGISTRATION AND INFORMATION:
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