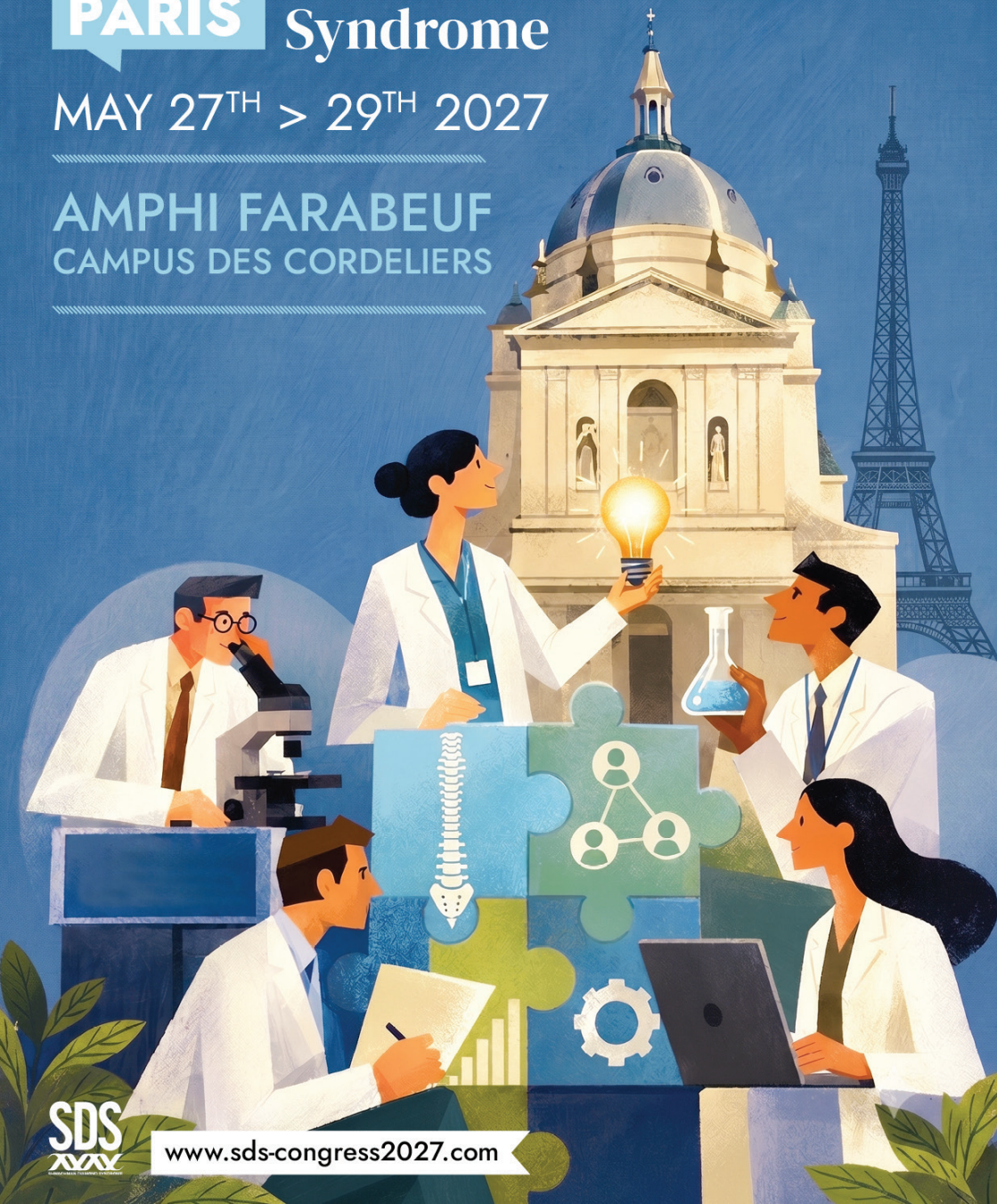
# 12th International Congress on Shwachman-Diamond Syndrome

PARIS

MAY 27TH > 29TH 2027

AMPHI FARABEUF
CAMPUS DES CORDELIERS



SDS

www.sds-congress2027.com

# Thursday, May 27



## 09H00 - 11H00

**SDS FAMILY AND SUPPORT ASSOCIATIONS**
**HOW TO DEVELOP A SUPPORT PATIENT AND PARENTS**
**EXCHANGE OF EXPERIENCE : DIFFICULTIES, ACHIEVEMENT, PERSPECTIVES**

## 11:00 - 11:45

**LUNCH BREAK - Family and support associations**

## 11:45 - 12:15

**WELCOME COFFEE**

## 12:15 - 12:30

**OPENING REMARKS**
*Jean DONADIEU & Kasiani MYERS*

## 12:30 - 14:00

SESSION 1

**LIVING WITH SDS**
Patient Family Interview.
Needs of the SDS Community. *Julia HAWKINS*
Where should the focus be in SDS research.
Questions & Answers.

## 14:00 - 15:30

SESSION 2

**SDS REGISTRY : A KEY TOOL TO IMPROVE THE KNOWEGE AND THE CARE**
Generality : Cohort and registry for Rare diseases. *Jean DONADIEU*
Generality : Experience of an international study. *Kasiani MYERS*
Registries in the world / organisation Success Difficulties.
*Akiko SHIMAMURA, Marco CIPOLLI, Kinichiro WATANABE, Cornelia ZEIDLER, Taco KUIJPERS & Eszter HARS*
Questions & Answers.

## 15:30 - 16:00

**BREAK**

## 16:00 - 16:15

SESSION 3

**LEARNING FROM AN INTERNATIONAL COOPERATION**
*Kasiani MYERS*

## 16:15 - 17:00

SESSION 4

**GUIDELINES**
*Jane KOO*

# Friday, May 28

## 08:00 - 09:15
SESSION 5

**PATHOPHYSIOLOGY OF SDS**

Ribosome : Archeology / Ontogen and the biological world. *Emmanuelle SCHMITT*
The Genetic of SDS. *Akiko SHIMAMURA*
Targeting the Ribosome. *Alan WARREN*
Hog1 /p38 ZAKa and SBDS. *Seth COREY*

## 09:15 - 10:45
SESSION 6

**FINDING / HYPOTHESIS**

SBDS and RNF2. *Masafumi YAMAGUCHI*
Inflammation and SDS. *Valentino BEZZERRI*
Eif6 inhibitors : Development and perspectives. *Christine HILCENKO*
Title to be announced. *Taco KUIJPERS*

## 10:45 - 11:05
**BREAK**

## 11:05 - 12:20
SESSION 7

**SDS NOT RELATED TO SBDS**

SRP54. *Manon DELAFOY*
ELF1. *Jean DONADIEU*
DNA JC21. *Marcin WLORDARSKY*

## 12:20-13:15
**LUNCH BREAK**

## 13:15 - 14:15
SESSION 8

**PETER DURIE MEMORIAL KEYNOTE : FROM DIAGNOSIS TO MANAGEMENT**

## 14:15-14:45
**BREAK**

## 14:45 - 17:00
SESSION 9

**HEMATOLOGY / MALIGNANICIES OF SDS FROM CLONAL HEMATOPOESIS TO MALIGNANCIES**

*Chair : Jean SOULIER*

Clonal hematopesis landscape in SDS. *Alyssa KENNEDY*
The dynamic of Cytopenia / myelodysplasia findings in the course of SDS. *Ygal DROR*
How to follow adult with SDS. *Flore SICRE DE FONTBRUNE*
Blood NGS vs Bone marrow monitoring. *Pierre HIRSCH*
When SDS turn bad ? can we identifed the key clonal hemato-poeitic event. *Kasiani MYERS*
How to transplant patients with SDS: MAC vs RIC. *Simone CESARO*
Solid tumors, Lymphoma in SDS. *Jean DONADIEU*

## 17:00
**SELECTED ORAL ABSTRACT PRESENTATIONS**

## 19:00
**GALA DINNER**

# Saturday, May 29



**08:00 - 09:15** SESSION 10

**REPRODUCTION MEDICINE IN SDS**

Fertility / pregancy in SDS. *Christine BELLANNE CHANTELOT*
Ante natal disgnosis in SDS. *Christel THAUVIN*
Ethical and medical issues.

**09:15 - 10:45** SESSION 11

**NON HEMATOLOGIC MANIFESTATIONS OF SDS**

Gastro intestinal. *Amit GROVER*
Bone. *Outi MÄKITIE*
Heart. *Quentin HAUET*
Weakness in SDS : can we measure it. *Pascal AMEDRO*

**10:45 - 11:05**

**BREAK**

**11:05 - 12:35** SESSION 12

**NEURODEVELOPMENT IN SDS**

Neurodevelopment phenotypes of SDS. *Elizabeth KERR*
Social insertion of young adult. *Sandra PEROBELLI*
Pragmatic and Cooperative Profiles. *Arthur TROGNON*
Discussion groups / by age.

**12:35 - 13:30**

**LUNCH BREAK**

**13:30 - 15:00** SESSION 13

**FUTURE DIRECTION**

New therapeutic approcah : Ataluren. *Valentino BEZZERRI & Marco CIPOLLI*
HSCT timing revidited. *Alyssa KENNEDY*
Optimising the transition from pediatric to adulhood. *Taco KUIJPERS & Flore SICRE DE FONTBRUNE*
Working together : an international SDS consortium. *Akiko SHIMAMURA*

**15:00 - 15:15**

**BREAK**

**15:15 - 16:30** SESSION 14

**WORKING TOGETHER : AN INTERNATIONA SDS CONSORTIUM**

Patients association network : proposal for the future. *Eszter HARS*
Professional network : international guidelines. *Jane KOO*

**16:30-17:00**

**CLOSING REMARKS**

*Manon DELAFOY*