

Newsletter May 2023 Issue 72

Letter from the President

Dear Friends,

There has been a lot of activity at the ECFS since the last edition of our newsletter and here is a brief review of the special projects, what's new with our society and a few highlights of the upcoming 46th European Cystic Fibrosis Conference taking place in a few days, this year in Vienna, Austria. But first, let me remind you of the ECFS elections, which are taking place this month.

Time flies! I personally will finish my term as president in 2024 and the new president will be elected this year in order to have a smooth transition. Prof. Jane Davies applied for President of the ECFS.

There are also two vacancies at the Board this year. Prof. Dorota Sands and Prof. Carsten Schwarz finish their terms and I wish to express my deepest thanks to both for their contribution to the Board over the past 3 years.

Four candidates applied for these positions as Board members: Prof. Jürg Barben (CH), Prof. Dorota Sands (PL), Prof. Carsten Schwarz (DE) and Prof. Mirjam Stahl (DE).

Your involvement in the ECFS Board elections is critical and will contribute to shape the future direction of the Society. It is essential that the Board has a strong and engaged membership to provide leadership to our Society. So, if you have not voted yet, please log in and vote <u>here</u> without delay.

The results of the elections will be announced at the Annual General Meeting (AGM) in Vienna on Friday 09 June (18:30-19:45, Hall G1). The AGM is open to all ECFS members having a valid 2023 membership and we very much hope that as many of you as possible will attend it. With the elections, the AGM is the moment where members can express their wishes and expectations for the Society. We value your involvement and hope to see more members contribute and input new ideas. More information on the AGM will appear further down in the newsletter.

The 20th ECFS Diagnostic Network Working Group Meeting took place in Montpellier in February, hosted by Dr. Caroline Raynal, and all agreed this was a fantastic meeting scientifically and with excellent networking opportunities.

The ECFS Basic Science Conference was held in Croatia this year, from 29 March to 01 April. Once again, the conference was a resounding success. We would like to thank the organisers, Nicoletta Pedemonte (IT), Alexandre Hinzpeter (FR) and Camille Ehre (US) for putting together a high-quality programme. The <u>abstract book is available</u> on the ECFS website.

We are rapidly approaching our annual conference in Vienna and the final preparations are well under way. The Scientific Committee has put together an outstanding programme and we have some exciting new basic research and results from clinical trials to discuss. You can find the <u>final</u> <u>programme</u> on the ECFS website. I would like to thank the Scientific Committee and the Steering Committee for all their hard work over the last year in preparing the programme, selecting the abstracts and sorting the various sessions. Besides the conference App featuring the programme and other useful information, other initiatives to note include the Interactive Master Class in Clinical CF, some 'meet the experts' sessions organised in the early morning and open to all, and the ECFS Tomorrow lounge which will feature a series of interactive sessions.

As part of our commitment to support young researchers, three Young Investigators Awards and twenty travel grants have been awarded to young investigators based on the merit of their abstract submissions. Congratulations to them for their prize!

Please don't miss a visit to the "CF Community" booth area in the Exhibition Hall for information on the various initiatives and programmes.

Many thanks, as always, to Dr. Henry Ryley for compiling the current references in Cystic Fibrosis included at the end of this Newsletter.

Please contact us if you have news items you would like to have included in future Newsletters or published on our website.

Yours sincerely,

Isabelle Fajac



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ECFS Board Elections

The European Cystic Fibrosis Society Board is holding elections for the ECFS President elect and two ECFS Board Members Positions.

Prof. Fajac will finish her term as president in 2024 and the new president will be elected this year to enable smooth handover of one year. We have received one application for President Elect and subsequently President of the ECFS sent by Prof. Jane Davies from Imperial college, London. As you all know, she is a paediatrician with many years of experience in CF and an international clinical scientist with a high level of experience in clinical trials. She is Deputy Editor of the Journal of Cystic Fibrosis. She is also an ECFS Board member and the ECFS Vice-President. In our constitution, and in the interest of democracy, we do require to have a vote on Jane Davies' application. There is an opportunity in the voting system not to endorse Jane's applicationif anyone wishes. President's Job Description



Jane Davies (UK)

Prof. Dorota Sands and Prof. Carsten Schwarz finish their terms and we wish to express our deepest thanks to both for their contribution to the Board over the past three years. The last couple of years were very special and we were lucky for their continued commitment to the Society.

We have received nominations for four candidates for those two vacant positions.

The Board should represent the ECFS membership in all aspects of our activities and should be drawn from a number of different European countries and reflect important areas of our activity.

The Society needs you to vote in large numbers so that your support for those elected and appointed to lead the Society is clearly expressed.

The online secured voting system can be found here.

POLLS CLOSE ON FRIDAY 02 JUNE 2023, 18:00 CEST



Jürg Barben (CH)

Board Member's Job Description.



Dorota Sands (PL)



Carsten Schwarz (DE)



Mirjam Stahl (DE)

ECFS Annual General Meeting

Save the date!

The Annual General Meeting will be held during the conference on Friday 09 June 2023 - From 18:30 to 19:45, in Hall G1 at the Austria Center Vienna. The Meeting will be organised in person. We need your active participation and look forward to a great discussion.

Upcoming Events

- ECFS Board Summer Meeting 06 June 2023 Vienna, Austria
- ECFS Annual General Meeting 09 June 2023 Vienna, Austria
- ERS Congress 09-13 September 2023 Milan, Italy
- North American Cystic Fibrosis Conference 02-04 November 2023 Phoenix AZ,US
- Adult Cystic Fibrosis Conference
 01-02 December 2023
 Milan, Italy
- ECFS Winter Meetings January 2024 Brussels, Belgium
- ECFS Diagnostic Network WG Meeting, February 2024
- Basic Science Conference, March 2024
- 47th European CF Conference 05-08 June 2024 Glasgow, UK

ECFS Annual General Meeting 2023 09 June 2023, Vienna, Austria

AGENDA

- 1. President's Report Isabelle Fajac
- 2. Secretary's Report Silke van Koningsbruggen-Rietschel
- 3. Treasurer's Report Barry Plant
- 4. ECFS Board Elections Isabelle Fajac
- 5. Update on Journal of Cystic Fibrosis Patrick Flume
- 6. ECFS CTN Report Damian Downey
- 7. ECFS Standards of Care Report Kevin Southern
- 8. ECFS Patient Registry Report Andreas Jung
- 9. ECFS Education Report Chris Smith
- 10. ECFS Working Group Reports:
 - Diagnostic Network Working Group
 - Exercise Working Group
 - Fungal Pathogens Working Group
 - Mental Health in the Era of CFTR Modulators Working Group
 - Neonatal Screening Working Group
 - Pulmonary Exacerbations Working Group
- 11. ECFS Special Interest Groups
 - ECFS Nursing Special Interest Group
 - European CF Pharmacy Special Interest Group
 - European CF Nutrition Special Interest Group
 - European Psychosocial Special Interest Group
 - ECFS Physiotherapy Special Interest Group
- 12. Presentation of the 2024 European CF Conference

47th EUROPEAN CYSTIC FIBROSIS CONFERENCE 5 – 8 JUNE 2024 | GLASGOW, UNITED KINGDOM





SAVE THE DATE

Registration and Abstract Submission Abstract Submission Deadline Notification of Abstract Acceptance Deadline for Early Registration

December 2023 15 January 2024 Mid-March 2024 21 March 2024

WWW.ECFS.EU/GLASG0W2024

#ECFS2024

Highlights of the Conference

The annual ECFS conference is taking place in Vienna, Austria this year. You can find all the details about the scientific programme <u>here</u>.

Below are some highlights of the conference. Looking forward to seeing you in Vienna!



MEET THE EXPERTS PROGRAMME

THURSDAY, JUNE 8, 07:30 - 08:20

- What's new in CF-related biofilm research?
- Diagnosis and management of CFTR-RD
- Management of haemoptysis in cystic fibrosis

FRIDAY, JUNE 9, 07:30 - 08:20

- How better characterisation of CFTR gene variants has helped our patients; will extended gene sequencing be a help or a hindrance?
- Remote psychological counselling tools and strategies
- Post SIMPLIFY what pulmonary therapies to rationalise and how to do it?

ECFS TOMORROW LOUNGE PROGRAMME

THURSDAY, JUNE 8	
12:45 - 13:45	Mental Health challenges in the era of new modulators
15:00-16:00	Dietetic management of the "well" person with CF
17:00-18:00	Psychosocial aspects of getting older with CF
FRIDAY, JUNE 9	
12:45 - 13:45	Optimising weight management - a multidisciplinary discussion
12:45 – 13:45	Research topics in CF nursing : how to get started

ECFS Conference App

The Conference App is always very popular and more than 83% of the delegates downloaded the app last year.

Via the App, you will find all the information on the scientific programme, the exhibitors, the abstracts and ePosters. The ECFS 2023 Conference App is designed to enhance the experience of the participants before, during and after the Conference and also contribute to reducing the printings and paper waste. Further information is available on the conference website and the App will soon be ready to download.

DOWNLOAD THE ECFS 2023

Access the detailed Conference Programme via the App:

- Interactive Conference Programme
- Abstracts and ePosters
- Vote via the App
- Information A-Z





Search for "ECFS 2023" in Apple App Store or Google Play Store The ECFS 2023 App is supported by ODDVIE



Meetings and Courses during the 2023 ECFS Conference

TUESDAY , JUNE 6	
08:30 - 16:45	Short Course – Exercise Testing – Practicalities and applications for Clinical practice**
08:30 - 18:00	ECFS Board Meeting*
12:30 - 17:00	Clinical Nutrition Course - Mastering new clinical expertise in emerging nutritional areas**
13:00 - 18:00	Psychodynamic aspects in chronic, medical illness**
15:00 - 18:00	ECFS-DNWG sweat test hands on workshop**
WEDNESDAY, JUNE 7	
08:30 - 13:30	Short Course – Exercise Testing – Practicalities and applications for Clinical practice**
08:30 - 12:45	CTN Training and Development*
09:00 - 14:30	The Essential Toolkit 2023 - A comprehensive overview of the changing face of CF **
09:00 - 16:00	ECFS Nursing Special Interest Group**
09:00 - 17:00	European Psychosocial Special Interest Group Meeting - Coping with change**
09:30 - 15:00	ECFS Neonatal Screening Working Group Annual Meeting
10:30 - 15:40	ECFS Cystic Fibrosis Nutrition Group Meeting**
13:45 - 17:00	ECFS Exercise Working Group Meeting*
13:30 - 16:30	ECFS CTN Training Research Coordinators*
13:30 - 17:30	European Cystic Fibrosis Pharmacy Group Meeting
13:30 - 17:30	ECFS CTN Steering Committee Meeting*
14:00 - 16:00	Physiotherapy Case Presentations
16:00 - 17:30	Global CF*
16:00 - 18:00	International Physiotherapy Group for Cystic Fibrosis (IPG/CF) Annual General Meeting
17:00 - 18:30	International (Global) CF Registry Group*
17:30 - 18:15	ECFS CTN Executive Committee Meeting*

* closed meeting
 ** extra registration required

THURSDAY , JUNE 8	
12:00 - 13:00	CTN – CFF – TDN – CanAct Meeting*
12:15 – 13:45	ECFS Education Committee meeting*
12:30 - 13:30	ECFS Patient Registry Statisticians Meeting*
12:30 - 14:00	ECFS Patient Registry spirometry workshop*
12:30 - 14:30	CTN Standardisation Committee Meeting*
12:30 - 15:00	ECFS Standards of Care Group Meeting*
13:30 - 14:30	ECFS Physiotherapy Special Interest Group (PhySIG) and IPG/CF committee meeting*
14:30 - 16:00	The Right to Breathe - CF modulators for every patient, everywhere!
15:00 - 16:00	CFTR2 Project*
18:00 - 19:00	ECFS Patient Registry Software training – Walk in session
18:30 - 20:00	ECFS CTN Standardisation sub-group meeting*
18:30 - 20:30	Pulmonary Exacerbation Working Group*
FRIDAY, JUNE 9	
12:00 - 14:00	ECFS CTN Lung Clearance Index Workshop
12:30 - 14:00	ECFS Mental Health in the Era of CFTR Modulators Working Group Meeting*
12:30 - 14:30	European Patient Registry Steering Group Meeting*
12:30 - 14:30	ECFS Diagnostic Network Working Group Meeting*
16:00 - 17:00	ECFS Patient Registry Software training
18:30 - 19:45	ECFS Annual General Meeting* - ECFS members only
SATURDAY , JUNE 10	
13:30 – 15:00	Scientific Committee Meeting – Glasgow 2024*

13:30 - 17:30 National Austrian Meeting (in German)

* closed meeting
 ** extra registration required

Pre-Conference Courses and workshop

Please note that full registration for the Annual ECFS-conference is not mandatory to participate in these preconference sessions. <u>Register now</u> !

Short Course – Exercise Testing – Practicalities and applications for clinical practice Tuesday 6 June & Wednesday 7 June 2023 - Vienna, Austria - 08:30-16:45 / 08:30-13:30



This course has been designed to give an overview of the practicalities of exercise testing, including CPET and submaximal tests. Discussions around suitability of different tests and interpretation of test data for clinical practice are included alongside talks on factors which influence exercise ability and participation and exercise for airway clearance. The course includes an expert panel discussion about selected clinical cases.

Clinical nutrition course – Mastering new clinical expertise in emerging nutritional areas

Tuesday 6 June 2023 - Vienna, Austria - 12:30 - 17:00

This course will aim to provide education and real world experience in the emerging clinical skills now required by the CF dietitian. The latest literature will be summarised and practical skills examined and discussed.

Psychosocial/Mental Health Course – Psychodynamic aspects in chronic, medical illness

Tuesday 6 June 2023 - Vienna, Austria - 13:00 - 18:00

The ECFS Conference this year takes place in Vienna, the city of Freud. It gives a great opportunity to explore how the psychodynamic aspects could be used in work with patients with cystic fibrosis.

Sweat test hands-on session 2023 (pre-ECFS conference workshop)

Tuesday 6 June 2023 - Vienna, Austria-15:00 - 18:00

This session is an ECFS-DNWG initiative, supported by the ECFSPR (pharmacovigilance programme) and ECFS Education. This hands-on session aims to support centres and help in problem solving to achieve acceptable standards for good sweat testing practice in their CF centre.

Four different methods to perform sweat testing will be available on site: the Macroduct advance[®] system, Macroduct 3700[®] system, the Gibson and Cooke sweat test method (gauze/filterpaper) and a conductivity system (Sweat Check).

The workshop is intended for lab technicians, biologists or nurses who perform sweat testing in the clinic or who are planning to start doing sweat testing in the near future and physicians who support the sweat test services in their centre.

Register here: <u>Sweat test hands-on session 2023 | European Cystic Fibrosis Society (ECFS)</u> Deadline for registration: 26 May 2023, 23:59 CEST

The Essential Toolkit 2023 - A Comprehensive overview of the changing face of CF

Wednesday 7 June- Vienna, Austria - 09:00-14:30

The 2023 version of The Essential Toolkit provides a dynamic and unique comprehensive overview of the changing face of cystic fibrosis (CF). This course is intended for medical and health care professionals involved in either adult and paediatric CF care and / or CF research, and provides a great opportunity to meet, learn and discuss the new era of CF with experts in the field.

It is also great fun! Participants will leave with principles and new skills to apply in practice.

Pre-course requirements: Basic knowledge on cystic fibrosis pathogenesis and clinical care is preferable, but not essential.

ECFS Award 2023

The ECFS Award is given annually to honour a person who has made an outstanding contribution to our basic understanding of cystic fibrosis or to the treatment or care of patients with cystic fibrosis. This year, the ECFS wishes to acknowledge Prof. Harm Tiddens.

HARM TIDDENS



Harm Tiddens was trained as a paediatrician in the Netherlands and he worked in the cystic fibrosis field most of his career. He is an internationally renowned paediatrician and scientist. He was Chairman of the CF team at Erasmus Medical Center in Rotterdam (NL) and he led several international programmes to improve the care of the very young with CF. He devoted his skills and energy to bring forward chest-CT Scan as a sensitive and accurate tool to diagnose and monitor lung disease in children. He initiated the ErasmusMC LungAnalysis, a core laboratory for digital image analysis of the lung in Rotterdam. He worked relentlessly to validate chest-CT as an outcome measure for care and clinical research, and he contributed to worldwide implementation of standardised chest

-CT techniques.

He was very involved in ECFS as a founding member of the ECFS-Clinical Trials Network, as a Board member and recently as President of the ECFS Conference in Rotterdam. He contributed enormously with his passion, dedication, and ideas. He champions working across countries and continents, and he has strong scientific links and research programmes in Australia, in the US and in China.

One of his many interests it to pass on his knowledge to the younger generation and he is a committed mentor and leader. He is a strong role model as an energetic clinical academic combining clinical care and research to improve outcomes in people with cystic fibrosis.

We are delighted that Harm Tiddens was granted the ECFS Award 2023 and look forward to hearing his talk at the European CF Conference Opening Plenary on 7 June, 2023 in Vienna.

Gerd Döring Award 2023

The Gerd Döring Award is an initiative of the European Cystic Fibrosis Society and is given annually to honour an exceptional young European scientist in their early career. The Award includes a monetary donation of 5,000 euro to support research. This year, the Award is given to Lúcia Santos in acknowledgement of her work.

LUCIA SANTOS



Lúcia Santos is a Biomedical Scientist who obtained her Ph.D. in Biology from the University of Lisbon. In the past six years, in collaboration with the University College Cork, her studies have been focused on the use of gene editing tools in order:

i) to understand the effects of different CF-causing mutations on the transcriptome and proteome of human bronchial epithelial cells;

II) to develop novel strategies to reverse the disease.

In her paper, Mutation-class dependent signatures outweigh disease-associated processes in cystic fibrosis cells (doi: 10.1186/s13578-023-00975-y), she combined transcriptome and proteome analysis to understand the global gene expression patterns associated with five prototypical CFTR mutations. The evaluation of the differentially expressed genes and proteins unveiled common and mutation-specific changes revealing functional signatures that are much more associated with the specific molecular defects associated with each mutation than the CFTR loss-of-function phenotype.

The combination of both datasets revealed that mutation-specific detected translated-transcripts (Dtt) have a high level of consistency. This study provides novel insight into the pathophysiology of CF and the mechanisms through which each mutation class causes disease and will likely contribute to the identification of new therapeutic targets and/or biomarkers for CF.

Lúcia will be presenting her research in Vienna at the Late Breaking Science session, scheduled on Friday, 9 June, 17:00-18:30.

ECFS 2023 – Young Investigators Award

Following the recommendations of the Steering Committee during the abstracts review process, the ECFS wishes to commend the quality of the work presented in the abstracts of some young investigators under the age of 35 having applied for the award.

The Young Investigator Award includes a monetary grant of € 750, a free registration to the Conference, and a 2023 ECFS membership subscription. We wish to extend our congratulations to the following Young Investigators:

SAMANTHA DURFEY



Samantha grew up in Tupper Lake, NY, a small town in upstate New York near a tuberculosis research centre. This early exposure to microbial research inspired Samantha to pursue her undergraduate degree in microbiology at the University of Alabama, Tuscaloosa. She then moved to the University of Washington, Seattle, to pursue a PhD under the guidance of Pradeep Singh. Samantha plans to pursue a postdoc studying immune responses to chronic infections.

About the at the 46th European CF Conference, abstract number WS13.06:

Regional bronchresearch presented oscopy sampling indicates that Pseudomonas aeruginosa infections persist throughout the lung after elexacaftor/tezacaftor/ivacaftor (ETI) due to intra-lung bacterial migration

Recent work suggests *Pseudomonas aeruginosa* (Pa) infections usually persist after elexacaftor/tezacaftor/ ivacaftor (ETI), but mechanisms of post-ETI infection are unknown. A leading hypothesis posits that lung segments with mild structural damage will clear infection, while those with severe damage will remain infected. To test this, we performed bronchoscopy in 9 adults, before and 1.5 years after they initiated ETI. We sampled the 2 highest and 3 lowest damaged lung segments in each subject. Six subjects remained infected after ETI. In these subjects, nearly all high and low-damage segments remained Pa-positive. Segments could remain infected because the local Pa present before ETI persist, or because Pa from other segments migrate to colonise these regions. We used whole genome sequencing of Pa isolates collected from each lung segment before and after treatment to distinguish these possibilities. Samantha will present these results and discuss the implications for future CF research.

FLORIANA GUIDA



Floriana was born in Sorrento (Naples, Italy) in 1995. She received a master's degree in molecular biology from University Federico II (Naples) in 2019. She performed her master's degree thesis and a postgraduate fellowship at TIGEM (Institute of Genetics and Medicine of Pozzuoli, Naples), then moved on to the University of Genoa, where she currently attends the second year of PhD in genetics, studying alternative targets for the treatment of cystic fibrosis basic defects.

About the research presented at the 46th European CF Conference, abstract number WS04.05: Alternative targets for the treatment of Cystic Fibrosis basic defect

Our research focuses on identifying novel therapeutic approaches for cystic fibrosis (CF). Correction of CF lung abnormalities may be obtained by restoring the function of CFTR with mutation-specific treatments. A potential alternative approach is to modulate the activity of other targets to stimulate CFTR-independent anion secretion or inhibit acidification. Despite the increasing interest towards possible alternative targets such as TMEM16A, SLC26A9, SLC26A4 and ATP12A, their precise function and expression in the airways are largely unknown or controversial, and specific modulators are still lacking. I will present the results of our research on expression and role of these targets in CF and non-CF airways, and our advances in finding drug candidates for the best targets. This could be essential for CF patients expressing undruggable CFTR mutants but could also be useful as an adjuvant therapy supporting the effect of CFTR rescue manoeuvres.

CHRISTIE MITRI



Christie Mitri is a Ph.D. graduate in Physiology, Physiopathology, and Therapeutics from Sorbonne University in Paris, France. Originally from Lebanon, she moved to France in 2017 to pursue her master's degree in Integrative Biology and Physiology. During her studies, Christie received a scholarship from Blanche and Vaincre la Mucoviscidose associations to work on developing innovative treatments for cystic fibrosis patients using antisense oligonucleotides under the supervision of Dr. Olivier Tabary. Christie is currently a postdoctoral researcher funded by the Foundation for Rare Diseases and is continuing her research to bring new treatments to cystic fibrosis patients.

About the research presented at the 46th European CF Conference, abstract number WS17.03: An alternative mutation agnostic therapy for Cystic Fibrosis with oligonucleotide antisense

CFTR correctors and potentiators have shown promising clinical outcomes, but alternative CFTR-independent strategies are still necessary for some patients. Our research focuses on activating an alternative chloride channel TMEM16a to compensate for the CFTR lack of activity. Previous studies demonstrated that miRNA-9 downregulates TMEM16A expression by binding to its 3'UTR mRNA. We developed an antisense oligonucleotide (TMEM16A ASO) that binds to the TMEM16A 3'UTR and prevents microRNA-9 from binding to the TMEM16A mRNA, therefore restoring TMEM16A expression and activity in the bronchial epithelia. I will present the results of in vitro and In vivo experiments studying TMEM16A ASO effectiveness, specificity and toxicity. TMEM16A ASO could be combined with CFTR modulators or TMEM16a potentiators to target multiple fronts, and this strategy could be applied to all people with CF.

2023 ECFS Basic Science Conference – Dubrovnik, Croatia



The ECFS Basic Science Conference was held in Dubrovnik, Croatia from 29 March to 01 April 2023. We would like to thank the organisers, Nicoletta Pedemonte (IT), Alexandre Hinzpeter (FR) and Camille Ehre (US) for putting together a high-quality programme. We welcomed 150 delegates and all were really happy to meet. The <u>abstract book</u> is available on the ECFS website.

Adult Cystic Fibrosis Conference



This conference, organised by the European Respiratory Society in partnership with the European Cystic Fibrosis Society, will provide an integrated approach to diagnosis, treatment, and continuous management of cystic fibrosis in adults.

This will be a hybrid event, with participants able to attend both online, and on-site in Milan, Italy.

The deadline for abstract submission is September 28, 2023.

The registration and abstract/clinical case submission are now open

More information

Meetings

Scientific Meeting (ScieM)

The ScieM takes place once a year in September with changing topics regarding recent research on cystic fibrosis (CF). It is organised by the Cystic Fibrosis Institute in collaboration with the German CF Research Community (FGM). The 22nd Scientific Meeting hosted by the scientific board of the Mukoviszidose e.V. (FGM) will take place on 28-29 September 2023 in Montabaur, Germany.

More information



SEE YOU IN VIENNA!



Please contact us if you have news items you would like to have included in future Newsletters or published on our website!

Email: david.debisschop@ecfs.eu



Current References in Cystic Fibrosis

Many thanks to Dr. Henry Ryley for compiling the current references in Cystic Fibrosis that you can download through this <u>link.</u>

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