E-mail letters for the SLOS Survey in 16 languages

[Ctrl+Click] to choose email letter with an English introduction followed by information in one of 16 languages

Contents

#BG Bulgarian with English introduction

The heading in the box of the email to the organisations:

Нов проект за лица със синдром на Смит-Лемли-Опитц и техните семейства

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

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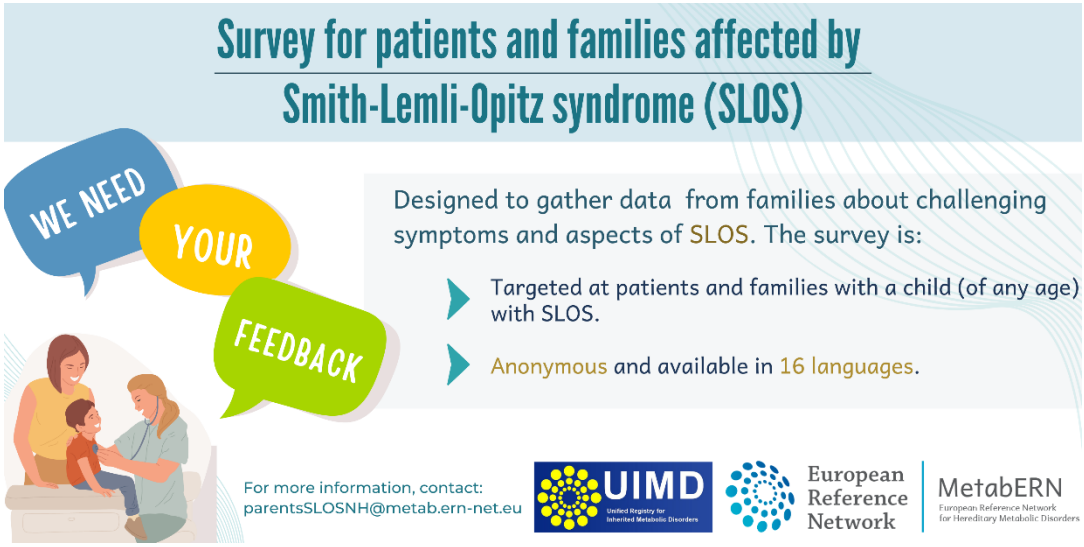
We have information about a new European project for persons with Smith-Lemli-Opitz syndrome and their families, the SLOS Natural History project. *More details are given in the enclosed letter* ***in Bulgarian*** *to the families.*



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Brief information about SLOS
SLOS is a metabolic disorder. The cause is an error in the synthesis of cholesterol in the body. That affects several biochemical processes in a complex way. Mildly affected persons may have no or minor inborn signs, near-normal cognitive function but often behavioural problems. A more severe impact of SLOS can be life threatening and involve malformations of many organs.

Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

BG Bulgarian
Нов проект за лица със синдром на Смит-Лемли-Опитц и техните семейства

Скъпо семейство с дете (на всяка възраст) със синдром на Смит-Лемли-Опитц,

Щастливи сме да Ви информираме за новия ни проект за лица със синдром на Смит-Лемли-Опитц (СЛОС), наречен Проект „Естествена История на СЛОС“ (SLOS Natural History Project)**.** Ние сме представители на пациентите в MetabERN за лица със синдром на Смит-Лемли-Опитц. MetabERN е Европейска Референтна Мрежа за Наследствени Метаболитни Заболявания, създадена от Европейския Съюз.

Подобряване на консултирането и разработка на терапии

Новият проект има за цел да подобри консултирането на семействата на лица със СЛОС и да създаде стратегии за терапевтични интервенции и дългосрочно здравеопазване. Проектът предвижда характеризиране на общите симптоми и редки състояния, както и честотата на нарушения на съня, аутизъм и сложно поведение, засягащи семействата.

Надяваме се да отговорите на кратко проучване (https://www.surveymonkey.com/r/DLHGDGB) за това кои симптоми и аспекти/характеристики на СЛОС Ви се струват съществени и представляват предизвикателство пред Вас, и ако се интересувате, да получите повече информация за проекта или да се присъедините към семейната мрежа.

Очакваме с нетърпение по-нататъшни контакти!
Информация за контакт: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe на Anne Kalweit
Представители на пациенти със СЛОС в MetabERN, подмрежа на PD.

#CZ Czech with English introduction

The heading in the box of the email to the organisations:

Nový projekt pro osoby se Smith-Lemli-Opitzovým syndromem a jejich rodiny

Dear organisation,

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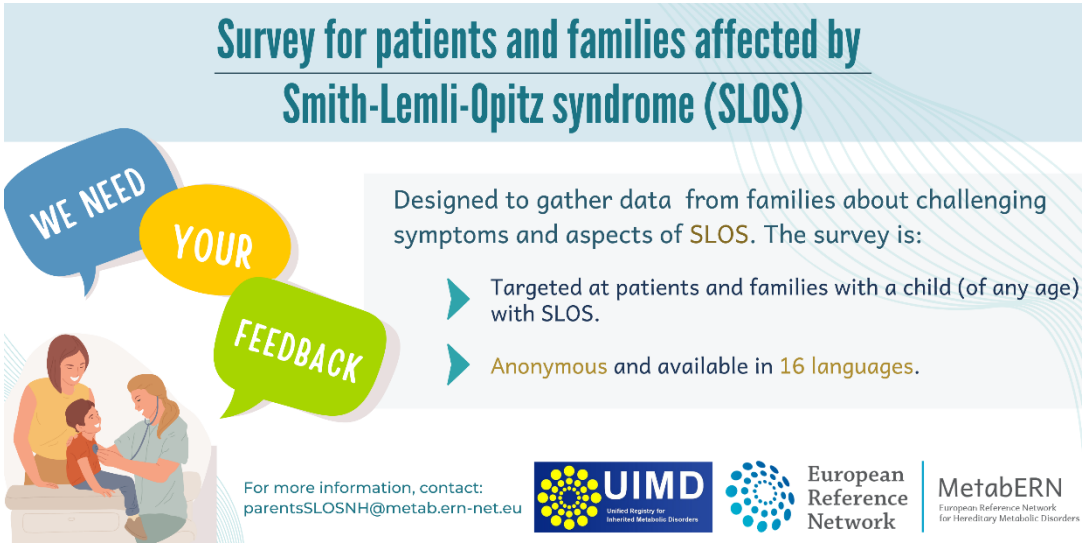

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

CZ Czech
Nový projekt pro osoby se Smith-Lemli-Opitzovým syndromem a jejich rodiny

Rádi Vás informujeme o novém projektu pro patienty se Smith-Lemli-Opitzovým syndrome (SLOS) – popis příznaků a obvklého průběhu nemoci. Jsme zástupci pacientů v MetabERN pro osoby se SLOS. MetabERN je evropská referenční síť pro dědičné metabolické poruchy, kterou zřídila EU.

Zlepšit poradenství a rozvíjet terapie
Cílem nového projektu je zlepšit poradenství rodin a vytvořit strategie pro léčebné zásahy a dlouhodobou zdravotní péči. Budou popsány obecné příznaky a vzácné stavy, stejně jako frekvence poruch spánku, autismu a komplexního chování postihujícího rodiny.

Doufáme, že se zapojíte do projektu a odpovíte na krátký průzkum (https://www.surveymonkey.com/r/2KY7DRD) o tom, které příznaky a aspekty SLOS považujete za důležité a náročné, a budete mít zájem získat více informací o projektu nebo se spojit s jinými rodinami. Odpovědi rodin, které ztratily jedno nebo více dětí v důsledku SLOS, jsou pro nás také velmi důležité a oceňujeme jakýkoli příspěvek.

Těšíme se na kontakt!
E-mailová adresa pro nás: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe a Anne Kalweit
Zástupci pacientů SLOS v MetabERN, podsítě PD

#DE German with English introduction

The heading in the box of the email to the organisations:

Projekt für Personen mit dem Smith-Lemli-Opitz Syndrom und ihre Familien

Dear organisation,

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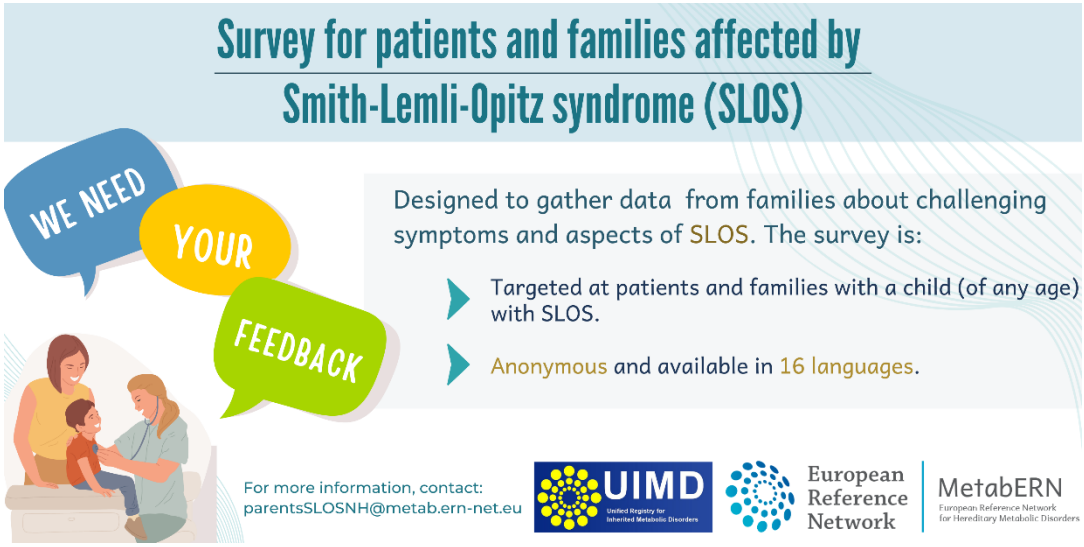

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

DE German
Projekt für Personen mit dem Smith-Lemli-Opitz Syndrom und ihre Familien

Liebe Familie mit einem Kind (in jedem Alter) mit Smith-Lemli-Opitz Syndrom,

Gerne informieren wir Sie über ein neues Projekt für Personen mit Smith-Lemli-Opitz Syndrom (SLOS), ***dem SLOS Natural History Projekt.*** Wir sind Patientenvertreter in MetabERN für Personen mit SLOS. MetabERN ist ein von der EU eingerichtetes Europäisches Referenznetzwerk für erbliche Stoffwechselstörungen.

Verbesserung der Beratung und Entwicklung von Therapien
Das neue Projekt zielt darauf ab, die Familienberatung zu verbessern und Strategien für therapeutische Interventionen und eine langfristige Gesundheitsversorgung zu entwickeln. Allgemeine Symptome werden ebenso beschrieben wie die Häufigkeit von Schlafstörungen, Autismus und komplexen Verhaltensstörungen, die die Familien betreffen.

Wir hoffen, dass Sie an einer kurzen Umfrage (https://www.surveymonkey.com/r/2K9F5WF) darüber teilnehmen, welche Symptome und Aspekte von SLOS Sie wesentlich und herausfordernd finden und ob Sie daran interessiert sind, mehr Informationen über das Projekt zu erhalten oder sich einem Familiennetzwerk anzuschließen. Antworten von Familien, die ein oder mehrere Kinder durch SLOS verloren haben, sind uns ebenfalls sehr wichtig und wir freuen uns über jeden Beitrag.

Wir freuen uns darauf, mit Ihnen in Kontakt zu treten!
E-Mail-Adresse an uns: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe und Anne Kalweit
Patientenvertreter für SLOS in MetabERN, das PD-Subnetwork

#DK Danish with English introduction

The heading in the box of the email to the organisations:

Et nyt projekt for personer med Smith-Lemli-Opitz syndrom og deres familier

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

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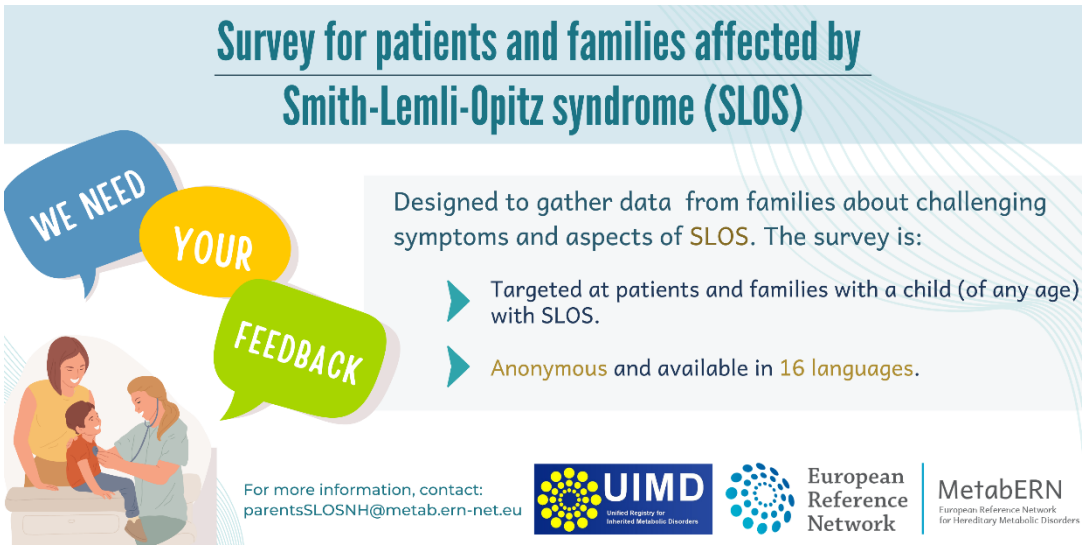

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

DK Danish
Et nyt projekt for personer med Smith-Lemli-Opitz syndrom og deres familier

Kære familie med et barn (uanset alder) med Smith-Lemli-Opitz syndrom,

Vi er glade for at informere dig om et nyt projekt for personer med Smith-Lemli-Opitz syndrom (SLOS***), SLOS Natural History-projektet.*** Vi er patientrepræsentanter i MetabERN for personer med SLOS. MetabERN er et europæisk netværk af referencecentre for medfødte stofskiftesygdomme, der er oprettet af EU.

Forbedre rådgivningen og udvikle terapier
Det nye projekt har til formål at forbedre rådgivningen af familier og fastlægge strategier for terapeutiske indgreb og langsigtet sundhedspleje. Generelle symptomer og sjældne tilstande vil blive beskrevet, og det samme gælder hyppigheden af søvnforstyrrelser, autisme og kompleks adfærd, der påvirker familierne.

Vi håber, at du vil besvare en kort undersøgelse (https://www.surveymonkey.com/r/2KSPLL3) af, hvilke symptomer og aspekter/funktioner af SLOS du finder væsentlige og udfordrende, og om du er interesseret i at få mere information om projektet eller slutte dig til et familienetværk. Svar fra familier, der har mistet et eller flere børn på grund af SLOS, er også meget vigtige for os, og vi sætter pris på ethvert input.

Vi glæder os til at komme i kontakt!
E-mail adresse til os: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe og Anne Kalweit
Patientrepræsentanter for SLOS i MetabERN, PD-undernetværket

#EL Greek with English introduction

The heading in the box of the email to the organisations:

Νέο πρόγραμμα για άτομα με σύνδρομο Smith-Lemli-Opitz και τις οικογένειές τους

Dear organisation,

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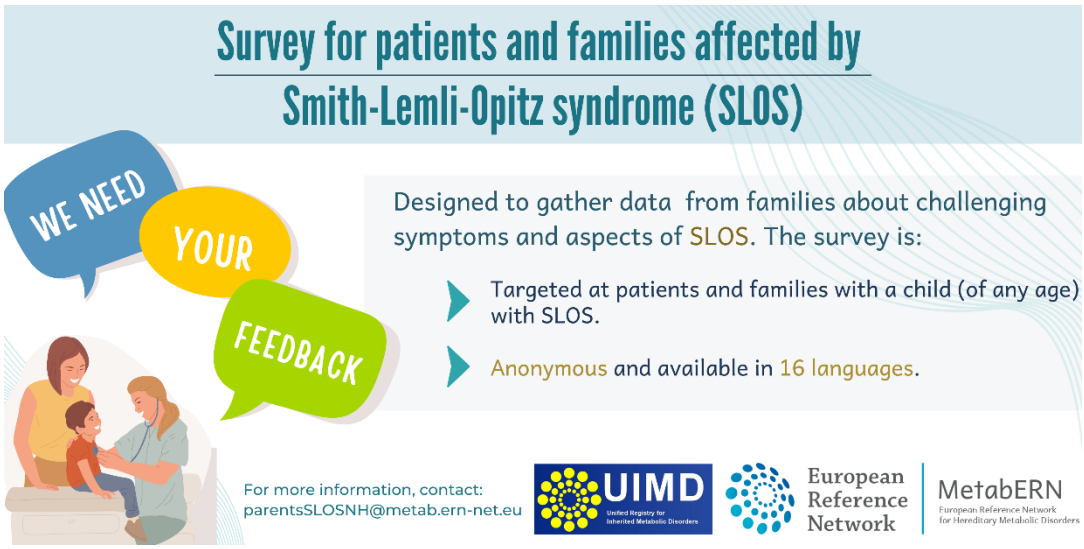

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

EL Greek

Νέο πρόγραμμα για άτομα με σύνδρομο Smith-Lemli-Opitz και τις οικογένειές τους

Αγαπητή οικογένεια με παιδί (κάθε ηλικίας) με σύνδρομο Smith-Lemli-Opitz,

Είμαστε στην ευχάριστη θέση να σας ενημερώσουμε για ένα νέο έργο για άτομα με σύνδρομο Smith-Lemli-Opitz (SLOS), ***το SLOS Natural History project.*** Είμαστε εκπρόσωποι ασθενών για το MetabERN για άτομα με SLOS. Το MetabERN είναι το Ευρωπαϊκό Δίκτυο Αναφοράς για τις κληρονομικές μεταβολικές διαταραχές, καθιερωμένο από την ΕΕ.

Βελτίωση της παροχής συμβουλών και ανάπτυξη θεραπειών
Το νέο πρόγραμμα αποσκοπεί στη βελτίωση της ενημέρωσης των οικογενειών και στην ανάπτυξη στρατηγικών για θεραπευτικές παρεμβάσεις και μακροχρόνια ιατρική περίθαλψη. Θα περιγράφονται τα γενικά συμπτώματα και σπάνιες καταστάσεις, όπως και η συχνότητα των διαταραχών ύπνου, ο αυτισμός και η πολύπλοκη συμπεριφορά που επηρεάζει τις οικογένειες.

Ευελπιστούμε ότι θα απαντήσετε σε ένα σύντομο ερωτηματολόγιο (https://www.surveymonkey.com/r/DL33YWC) σχετικά με τα συμπτώματα και τις πτυχές/χαρακτηριστικά του SLOS που θεωρείτε ιδιαίτερα σημαντικά και δύσκολα και με το αν ενδιαφέρεστε να λάβετε περισσότερες πληροφορίες για το πρόγραμμα ή να ενταχθείτε σε ένα οικογενειακό δίκτυο.

Ανυπομονούμε να έρθουμε σε επαφή μαζί σας!
Διεύθυνση ηλεκτρονικού ταχυδρομείου: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe και Anne Kalweit
Εκπρόσωποι ασθενών με SLOS στο MetabERN, το υποδίκτυο PD

#EN English for persons or families

The heading in the box of the email to the organisations:

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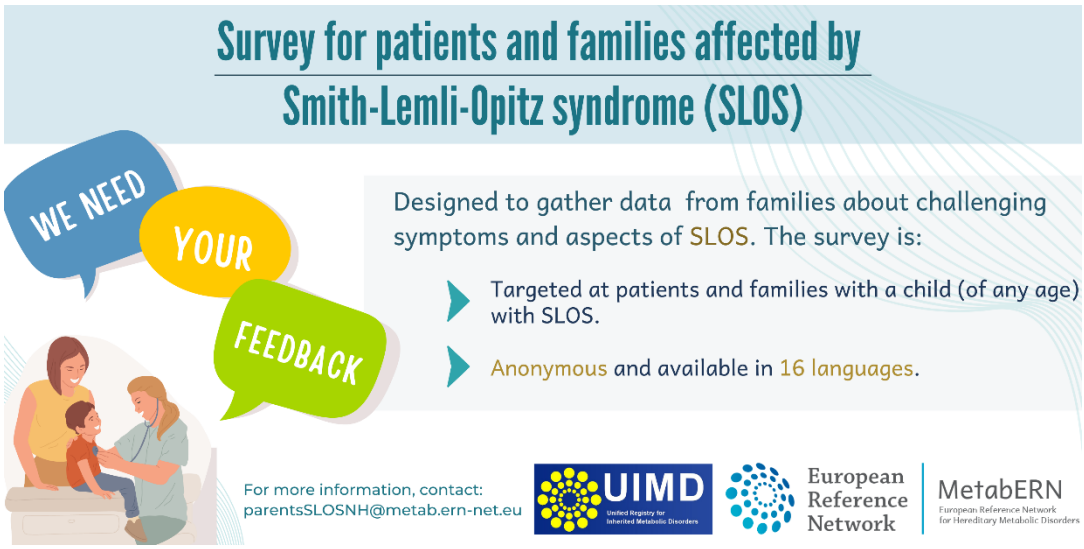

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Karin Mossler, Antje Enekwe and Anne Kalweit,

Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

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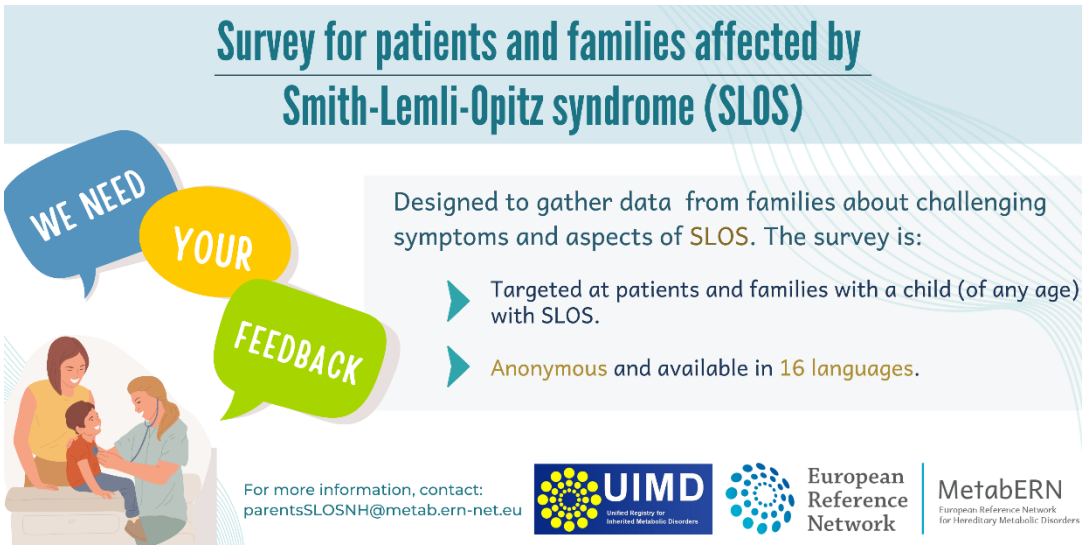

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

#ES Spanish with English introduction

The heading in the box of the email to the organisations:

Un nuevo proyecto para personas con síndrome de Smith-Lemli-Opitz y sus familias

Dear organisation,

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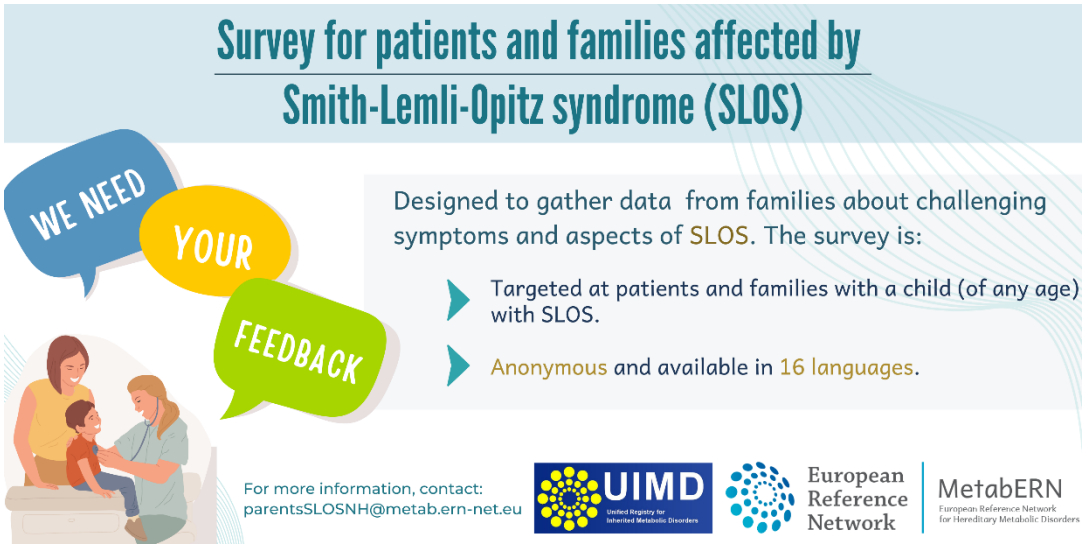

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Pa0tient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

ES Spanish

Un nuevo proyecto para personas con síndrome de Smith-Lemli-Opitz y sus familias

Querida familia con un hijo (de cualquier edad) que padece el síndrome de Smith-Lemli-Opitz,

Nos complace informarle acerca de la creación de un nuevo proyecto para personas con síndrome de Smith-Lemli-Opitz (SLO), el Proyecto Historia Natural del síndrome de SLO. Somos representantes de pacientes en MetabERN que padecen el síndrome de SLO. MetabERN es una red europea de referencia, establecida por la UE para trastornos metabólicos hereditarios.

Perfeccionamiento en el asesoramiento y el desarrollo de terapias
El nuevo proyecto tiene por objetivo mejorar el asesoramiento a las familias y desarrollar estrategias para alcanzar intervenciones terapéuticas y asistencia sanitaria a largo plazo. Se describirán las principales y menores manifestaciones clínicas, así como la frecuencia de trastornos de sueño, de autismo y de comportamiento que afectan a las familias.

Le agradeceriamos respondiera a una breve encuesta (https://www.surveymonkey.com/r/2KTG3HW) sobre los síntomas y aspectos/características de síndrome de SLO que Vd. encuentre importantes y desafiantes. Asimismo háganos por favor saber, si está interesado en obtener más información sobre el proyecto o unirse a una red familiar. Las respuestas de las familias que han perdido uno o más hijos debido a SLOS también son muy importantes para nosotros y apreciamos cualquier aporte.

¡Sería una enorme satisfacción para nosotros estar en contacto con Vd!
Nuestra dirección de correo electrónico: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe y Anne Kalweit
Representantes de pacientes para el síndrome de SLO en MetabERN, la subred de PD

#FR French with English introduction

The heading in the box of the email to the organisations:

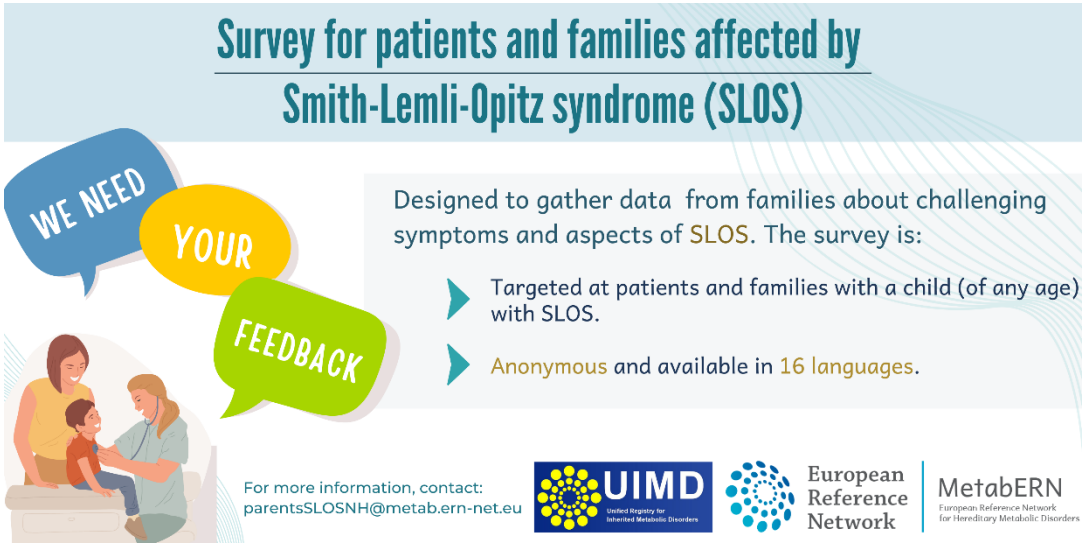
Un nouveau projet pour les personnes atteintes du syndrome de Smith-Lemli-Opitz et leurs familles

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

We are patient representatives in MetabERN for persons with the rare inherited metabolic disorder Smith-Lemli-Opitz syndrome (SLOS). MetabERN is a European Reference Network on Hereditary Metabolic Disorders, established by the EU.

We have information about a new European project for persons with Smith-Lemli-Opitz syndrome and their families, the SLOS Natural History project. *More details are given in the enclosed letter* ***in French*** *to the families.*



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Please contact us at ***email*** parentsSLOSNH@metab.ern-net.eu if you want *the longer information letter in another language or if you want more information* about the project, clarifications of wordings or medical terms.

Brief information about SLOS
SLOS is a metabolic disorder. The cause is an error in the synthesis of cholesterol in the body. That affects several biochemical processes in a complex way. Mildly affected persons may have no or minor inborn signs, near-normal cognitive function but often behavioural problems. A more severe impact of SLOS can be life threatening and involve malformations of many organs.

Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

FR French
Un nouveau projet pour les personnes atteintes du syndrome de Smith-Lemli-Opitz et leurs familles

Chère famille avec un enfant (de tout âge) atteint du syndrome de Smith-Lemli-Opitz,

Nous sommes heureux de vous informer sur un nouveau projet pour les personnes avec du syndrome de Smith-Lemli-Opitz (SLOS), ***le projet SLOS Natural History.*** Nous sommes des représentants des patients au MetabERN pour les personnes atteintes du syndrome de SLO. MetabERN est un réseau européen de référence sur les troubles métaboliques héréditaires, créé par l'UE.

Améliorer le counseling et développer des thérapies
Le nouveau projet vise à améliorer le conseil des familles et à établir des stratégies pour les interventions thérapeutiques et les soins de santé à long terme. Les symptômes généraux et les affections rares seront décrits, de même que la fréquence des troubles du sommeil, de l'autisme et des comportements complexes qui affectent les familles.

Nous espérons que vous répondrez à une brève enquête (https://www.surveymonkey.com/r/D857SX2) sur les symptômes et les aspects/caractéristiques de SLOS que vous trouvez essentiels et difficiles et si vous souhaitez obtenir plus d'informations sur le projet ou rejoindre un réseau familial.
Les réponses des familles qui ont perdu un ou plusieurs enfants à cause du SLOS sont également très importantes pour nous et nous apprécions toute contribution.

Nous sommes impatients d'être en contact!
Adresse e-mail pour nous: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe et Anne Kalweit
Représentants des patients pour SLOS à MetabERN, le sous-réseau PD

#HU Hungarian with English introduction

The heading in the box of the email to the organisations:

Új projekt a Smith-Lemli-Opitz szindrómában szenvedők és családjaik számára

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

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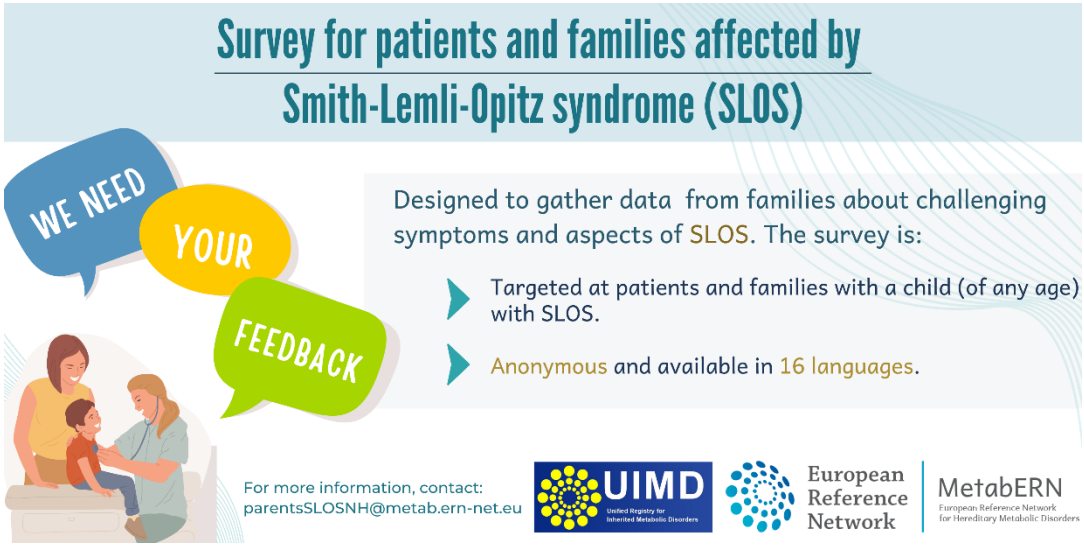
We have information about a new European project for persons with Smith-Lemli-Opitz syndrome and their families, the SLOS Natural History project. *More details are given in the enclosed letter* ***in Hungarian*** *to the families.*



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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

HU Hungarian
Új projekt a Smith-Lemli-Opitz szindrómában szenvedők és családjaik számára

Kedves család (bármilyen korú) Smith-Lemli-Opitz szindrómával,

Örömmel tájékoztatjuk Önt egy új projektről, amely az Smith-Lemli-Opitz szindrómában (SLOS). Természettudományi projekttel, ***az SLOS-szal rendelkezők számára készült.*** Mi vagyunk a betegek képviselői a MetabERN ben a SLOS szenvedők számára. A MetabERN az EU által létrehozott, az örökletes metabolikus rendellenességekkel foglalkozó európai referenciahálózat.

A tanácsadás javítása és terápiák fejlesztése
Az új projekt célja a családok tanácsadásának javítása, valamint a terápiás beavatkozásokra és a hosszú távú egészségügyi ellátásra vonatkozó stratégiák kidolgozása. Általános tüneteket és ritka állapotokat írunk le, csakúgy, mint az alvászavarok, az autizmus és a családokat érintő összetett viselkedés gyakoriságát.

Reméljük, hogy válaszol egy rövid felmérésre ((https://www.surveymonkey.com/r/2KN7HYC) hogy az SLOS mely tüneteit és szempontjait/jellemzőit tartja lényegesnek és kihívást jelentőnek, és ha szeretne több információt kapni a projektről, vagy csatlakozni egy családi hálózathoz.
Azon családok válaszai szintén nagyon fontosak számunkra, akik egy vagy több gyermeküket elveszítették SLO szindróma miatt.

Alig várjuk, hogy kapcsolatba léphessünk!
E-mail címünk: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe és Anne Kalweit
Az SLOS betegképviselői a MetabERN-ben, a PD alhálózatban

#IT Italian with English introduction

The heading in the box of the email to the organisations:

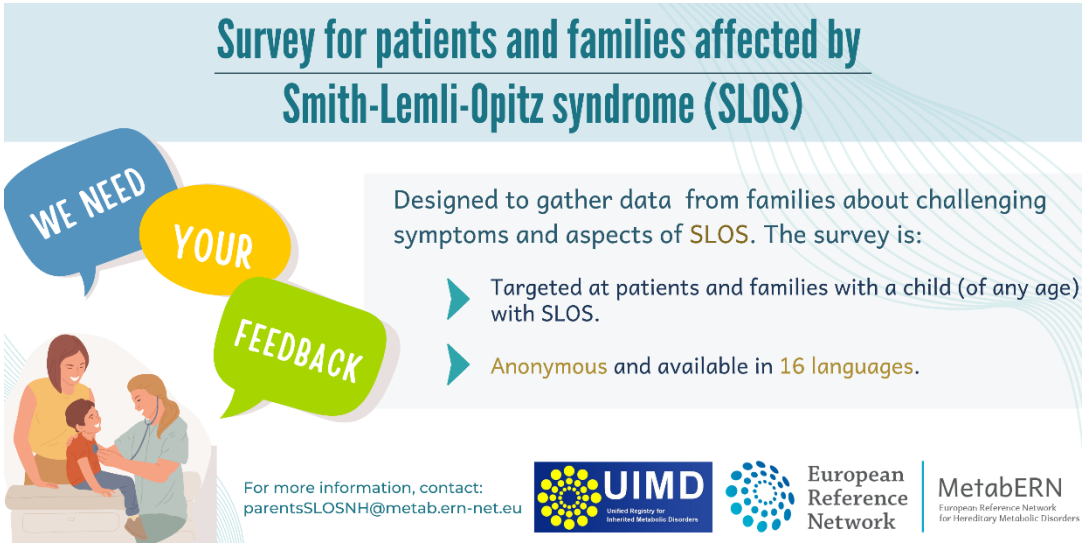
Un nuovo progetto per le persone con la sindrome di Smith-Lemli-Opitz e le loro famiglie

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

We are patient representatives in MetabERN for persons with the rare inherited metabolic disorder Smith-Lemli-Opitz syndrome (SLOS). MetabERN is a European Reference Network on Hereditary Metabolic Disorders, established by the EU.

We have information about a new European project for persons with Smith-Lemli-Opitz syndrome and their families, the SLOS Natural History project. *More details are given in the enclosed letter* ***in Italian*** *to the families.*



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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

IT Italian

Un nuovo progetto per le persone con la sindrome di Smith-Lemli-Opitz e le loro famiglie

Cara famiglia con un bambino (di qualsiasi età) con sindrome di Smith-Lemli-Opitz,

Siamo lieti di informarvi su un nuovo progetto per le persone di Smith-Lemli-Opitz (SLOS), ***il progetto di Storia Naturale SLOS.*** Siamo rappresentanti dei pazienti in MetabERN per le persone affette dalla sindrome SLOS. MetabERN è una rete europea di riferimento sui disturbi metabolici ereditari, istituita dall'UE.

Migliorare la consulenza e sviluppare le terapie
Il nuovo progetto mira a migliorare la consulenza delle famiglie e a stabilire strategie per gli interventi terapeutici e l'assistenza sanitaria a lungo termine. Saranno descritti sintomi generali e condizioni rare, così come la frequenza di disturbi del sonno, autismo e comportamenti complessi che colpiscono le famiglie.

Ci auguriamo che risponderà a un breve sondaggio (https://www.surveymonkey.com/r/2K2WKCJ) su quali sintomi e aspetti/caratteristiche di SLOS trovi essenziale e impegnativo e se sei interessato a ottenere maggiori informazioni sul progetto o a entrare in una rete familiare.
Anche le risposte delle famiglie che hanno perso uno o più figli a causa di SLOS sono molto importanti per noi e apprezziamo qualsiasi input.

Non vediamo l'ora di essere in contatto!
Indirizzo e-mail a noi: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe e Anne Kalweit
Rappresentanti dei pazienti per SLOS in MetabERN, la sottorete PD

#NL Dutch with English introduction

The heading in the box of the email to the organisations:

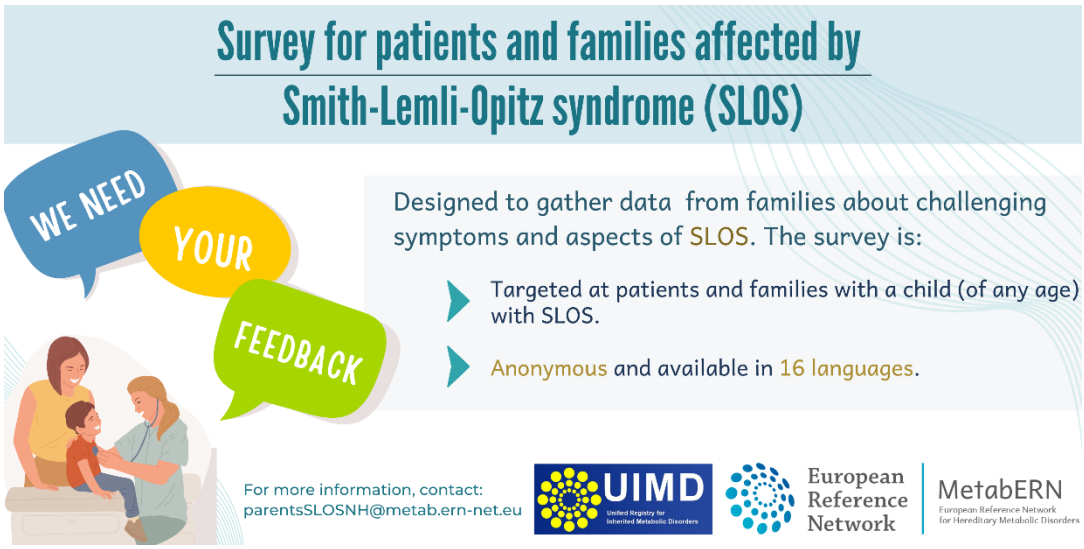
Een nieuw project voor personen met Smith-Lemli-Opitz syndroom en hun families

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

We are patient representatives in MetabERN for persons with the rare inherited metabolic disorder Smith-Lemli-Opitz syndrome (SLOS). MetabERN is a European Reference Network on Hereditary Metabolic Disorders, established by the EU.

We have information about a new European project for persons with Smith-Lemli-Opitz syndrome and their families, the SLOS Natural History project. *More details are given in the enclosed letter* ***in Dutch*** *to the families.*



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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

NL Dutch
Een nieuw project voor personen met Smith-Lemli-Opitz syndroom en hun families

Beste familie met een kind (van elke leeftijd) met Smith-Lemli-Opitz syndroom,

Wij informeren u graag over een nieuw project voor personen met Smith-Lemli Opitz syndroom (SLOS), ***het SLOS Natural History project.*** Wij zijn patiëntenvertegenwoordigers in MetabERN voor personen met het SLOS. MetabERN is een Europees referentienetwerk voor erfelijke metabole aandoeningen, opgericht door de EU.

Verbeteren van advisering en van ontwikkeltherapieën
Het nieuwe project heeft tot doel de begeleiding van gezinnen te verbeteren en strategieën voor therapeutische interventies en langdurige gezondheidszorg vast te stellen. Algemene symptomen en zeldzame kenmerken van SLOS zullen worden beschreven, evenals bijvoorbeeld slaapstoornissen, autisme en complex gedrag dat de families treft.

We hopen dat u een korte enquête (https://www.surveymonkey.com/r/D8FCCW8) wilt beantwoorden over welke symptomen en aspecten/kenmerken van SLOS u essentieel en uitdagend vindt. Bovendien willen we graag weten of u geïnteresseerd bent in het verkrijgen van meer informatie over het project of om deel te nemen aan een familienetwerk. Antwoorden van gezinnen die een of meer kinderen hebben verloren als gevolg van SLOS zijn ook erg belangrijk voor ons en we zouden het op prijs stellen als u de enquête wilt invullen. We waarderen elke inbreng.

We kijken ernaar uit om in contact te komen!
E-mailadres aan ons: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe en Anne Kalweit
Patiëntenvertegenwoordigers voor SLOS in MetabERN, het PD-subnetwerk

#NO Norwegian with English introduction

The heading in the box of the email to the organisations:

Et nytt prosjekt for personer med Smith-Lemli-Opitz syndrom og deres familier

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

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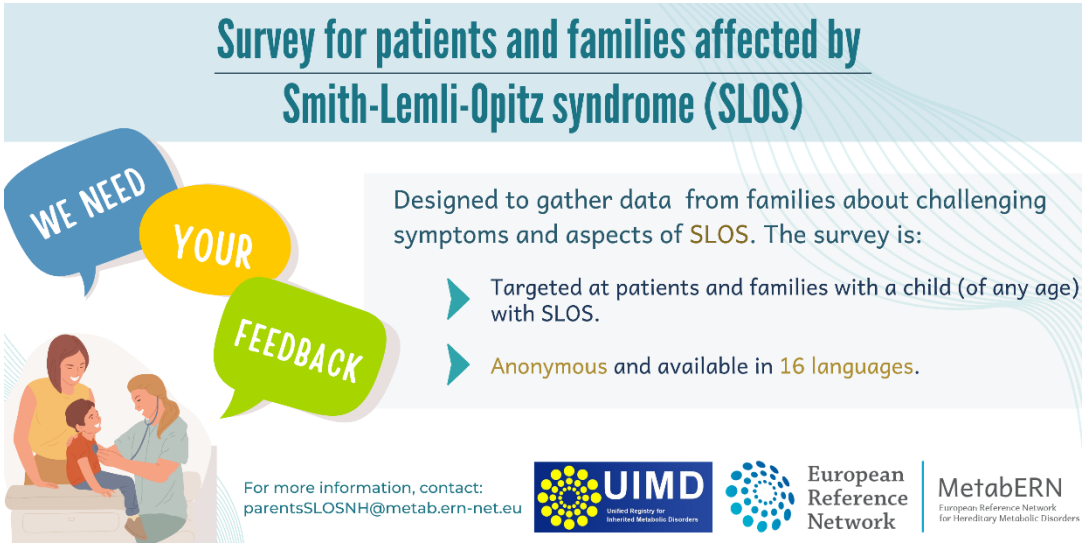

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

NO Norweigan
Et nytt prosjekt for personer med Smith-Lemli-Opitz syndrom og deres familier

Kjære familie med et barn (i alle aldre) med Smith-Lemli-Opitz syndrom,

Vi informerer deg herved om et nytt prosjekt for personer med Smith-Lemli-Opitz syndrome (SLOS), nemlig SLOS ***Natural History-prosjektet (studie på det naturlige forløpet av SLOS). Vi som er ansvarlige for prosjektet er pasientrepresentanter i MetabERN for pasienter med SLOS***. MetabERN er et europeisk referansenettverk om arvelige metabolske lidelser, opprettet av EU.

Forbedre veiledning og utvikle behandling
Dette prosjektes målsetning er å forbedre veiledning for familier og fremme strategier for å bedre behandling av SLOS og forbedre livsløps-helsen. Vi ønsker å beskrive symptomer, sjeldne funn, søvnforstyrrelser, autisme og adferdensendringer som kan påvirke familien.

Vi håper du vil svare på en kort undersøkelse (https://www.surveymonkey.com/r/2KX8RNM) om hvilke symptomer og aspekter/forholdved SLOS du synes er viktig og utfordrende, og hvis du er interessert i å få mer informasjon om prosjektet eller bli med i et familienettverk så er du hjertelig velkommen til det. Svar fra familier som har mistet ett eller flere barn på grunn av SLOS er også svært viktige for oss og vi setter pris på alle tilbakemeldinger.

Vi ser frem til å komme i kontakt med deg!
E-postadresse til oss: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe og Anne Kalweit
Pasientrepresentanter for SLOS i MetabERN, undernettverket PD

#PL Polish with English introduction

The heading in the box of the email to the organisations:

Nowy projekt dla osób z zespołem Smitha-Lemli-Opitza i ich rodzin

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

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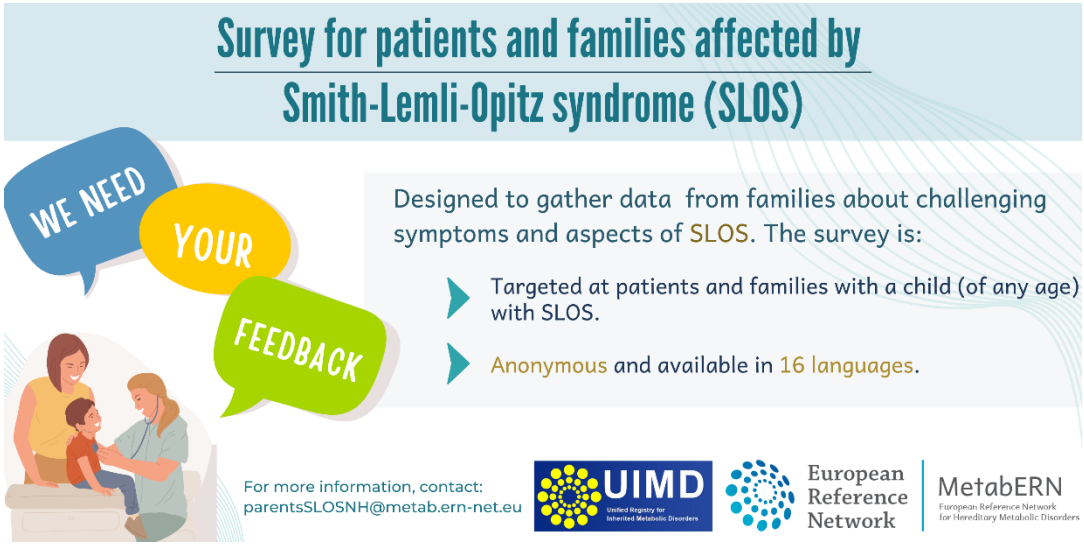

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

PL Polish
Nowy projekt dla osób z zespołem Smitha-Lemli-Opitza i ich rodzin

Droga rodzina z dzieckiem (w każdym wieku) z zespołem Smitha- Lemli-Opitza,

Z przyjemnością informujemy o nowym projekcie dla osób z Smitha-Lemli-Opitza (SLOS), ***projektem SLOS Natural History.*** Jesteśmy przedstawicielami pacjentów w MetabERN dla osób z zespołem SLOS. MetabERN jest europejską siecią referencyjną ds. dziedzicznych zaburzeń metabolicznych, utworzoną przez UE.

Ulepszyć doradztwo i rozwijać terapie
Nowy projekt ma na celu poprawę doradztwa dla rodzin oraz opracowanie strategii interwencji terapeutycznych i długoterminowej opieki zdrowotnej. Zostaną opisane ogólne objawy i rzadkie zaburzenia, a także częstotliwość zaburzeń snu, autyzm oraz złożone zachowania mającеh wpływ na rodziny.

Mamy nadzieję, że odpowiesz na krótką ankietę (https://www.surveymonkey.com/r/2KWQH89) o tym, jakie objawy i aspekty/cechy SLOS uważasz za najważniejsze i najbardziej wymagające dla pacjentów orazjeśli jesteś zainteresowany uzyskaniem dodatkowych informacji na temat projektu lub dołączeniem do sieci rodzinnej.
Odpowiedzi od rodzin, które straciły jedno lub więcej dzieci z powodu SLOS, są dla nas również bardzo ważne i doceniamy wszelkie uwagi na ten temat.

Z niecierpliwością czekamy na kontakt!
Adres e-mail do nas: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe i Anne Kalweit
Przedstawiciele pacjentów dla SLOS w MetabERN, podsieci PD

#PT Portuguese with English introduction

The heading in the box of the email to the organisations:

Um novo projeto para pessoas com síndrome de Smith-Lemli-Opitz e suas famílias

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

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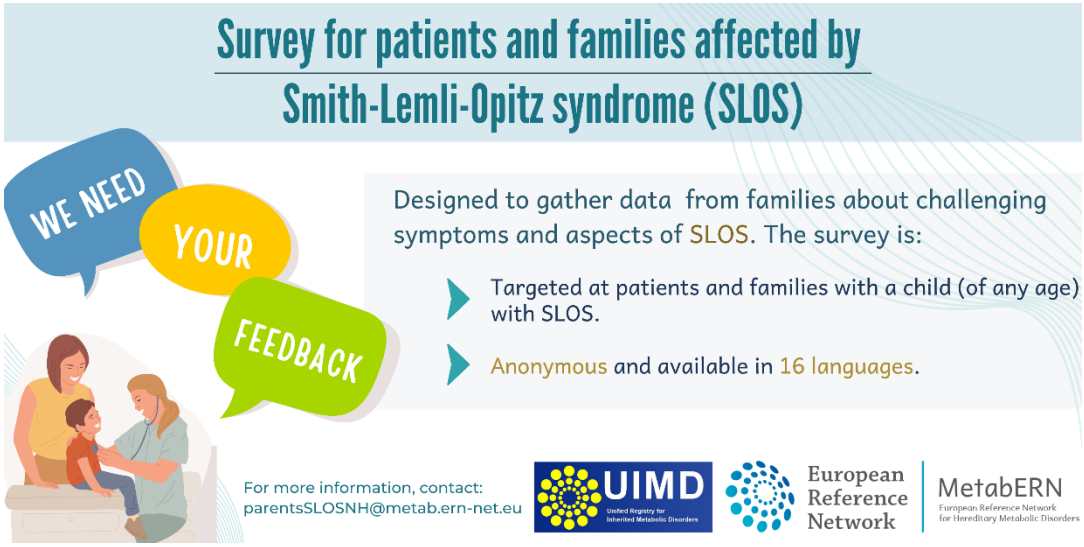

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Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

PT Portuguese

Um novo projeto para pessoas com síndrome de Smith-Lemli-Opitz e suas famílias

Querida família com uma criança (de qualquer idade) com síndrome de Smith-Lemli-Opitz,

Temos o prazer de informá-lo sobre um novo projeto para pessoas com síndrome de Smith-Lemli-Opitz (SLOS), o projeto da História Natural do SLOS. Somos representantes de doentes na MetabERN para pessoas com SLOS. A MetabERN é uma Rede Europeia de Referência em Doenças Hereditárias Metabólicas, criada pela UE.

Melhorar o aconselhamento e desenvolver terapias

O novo projeto visa melhorar o aconselhamento das famílias e estabelecer estratégias para intervenções terapêuticas e cuidados de saúde a longo prazo. Sintomas gerais e condições raras serão descritos, assim como a frequência de distúrbios do sono, autismo e comportamentos complexos que afetam as famílias.

Esperamos que responda a um curto questionário (https://www.surveymonkey.com/r/28DXSGB) sobre quais os sintomas e aspetos/características do SLOS que acha essenciais e desafiadores e se está interessado/a em obter mais informações sobre o projeto ou entrar numa rede de famílias. As respostas das famílias que perderam uma ou mais crianças devido ao SLOS são também muito importantes para nós e agradecemos qualquer contributo.

Estamos ansiosos para estar em contato!
Endereço de e-mail para nós: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe e Anne Kalweit
Representantes de doentes para o SLOS na MetabERN, a sub-rede PD

#RO Romanian with English introduction

The heading in the box of the email to the organisations:

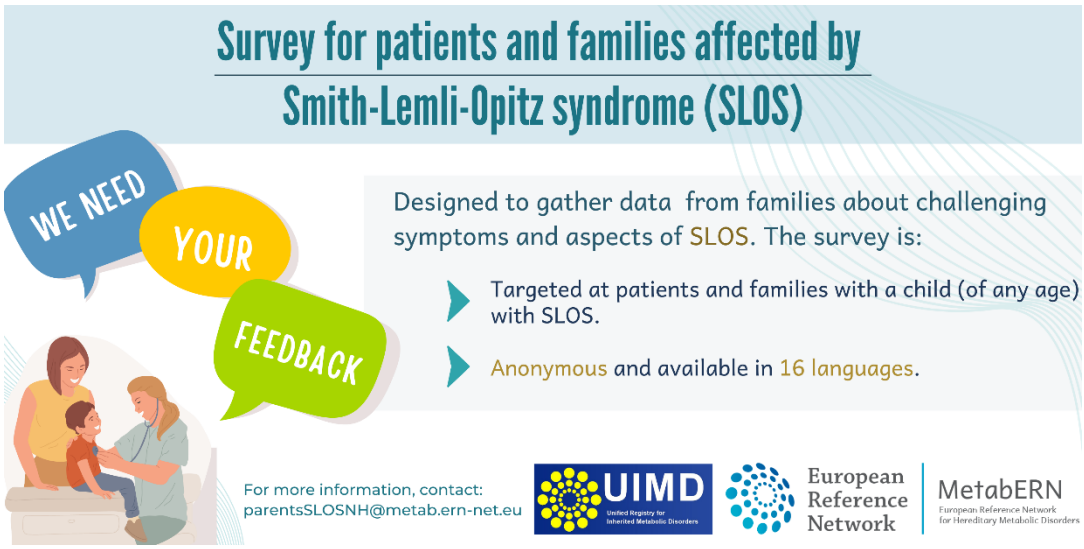
Un nou proiect pentru persoanele cu sindrom Smith-Lemli-Opitz și familiile acestora (indiferent de vârsta pacientului)

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

We are patient representatives in MetabERN for persons with the rare inherited metabolic disorder Smith-Lemli-Opitz syndrome (SLOS). MetabERN is a European Reference Network on Hereditary Metabolic Disorders, established by the EU.

We have information about a new European project for persons with Smith-Lemli-Opitz syndrome and their families, the SLOS Natural History project. *More details are given in the enclosed letter* ***in Romanian*** *to the families.*



We enclose a file with links to the SLOS survey in 16 languages and an English version of the letter.

The information have been computer translated and checked by persons from each country. We hope the translation is OK, if not please forgive errors that may have occurred.

Please contact us at ***email*** parentsSLOSNH@metab.ern-net.eu if you want *the longer information letter in another language or if you want more information* about the project, clarifications of wordings or medical terms.

Brief information about SLOS
SLOS is a metabolic disorder. The cause is an error in the synthesis of cholesterol in the body. That affects several biochemical processes in a complex way. Mildly affected persons may have no or minor inborn signs, near-normal cognitive function but often behavioural problems. A more severe impact of SLOS can be life threatening and involve malformations of many organs.

Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

RO Romanian

Un nou proiect pentru persoanele cu sindrom Smith-Lemli-Opitz și familiile acestora (indiferent de vârsta pacientului)

Dragă familie a unui copil cu sindromul Smith-Lemli-Opitz (SLOS)

Suntem bucuroși să vă informăm de existența proiectului ***SLOS Natural History*** (**Evoluția naturală a SLOS**) consacrat persoanelor cu sindrom Smith-Lemli-Opitz (SLOS). Suntem reprezentanți ai pacienților în MetabERN pentru persoanele cu SLOS. MetabERN este o rețea europeană de referință privind tulburările metabolice ereditare, înființată de UE.

Îmbunătățirea consilierii și descoperirea de tratamente
Noul proiect își propune să îmbunătățească consilierea familiilor și să stabilească strategii pentru intervenții terapeutice și îngrijirea medicală pe termen lung. Ne interesează atât simptomele generale cât și particularitățile, precum frecvența tulburărilor de somn, a autismului și comportamentului complex care afectează viața familiilor.

Sperăm că veți răspunde la un scurt sondaje (https://www.surveymonkey.com/r/2K56N92) despre simptomele și aspectele/trăsăturile SLOS pe care le considerați esențiale și că sunteți interesat să obțineți mai multe informații despre proiect sau să vă alăturați unei comunități a familiilor. Informațiile pe care ni le pot furniza familiile care au pierdut un copil (sau mai mulți) cu SLOS pot fi foarte utile și am aprecia participarea lor.

Așteptăm cu nerăbdare să luați legătura cu noi!
Adresa e-mail: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe și Anne Kalweit
Reprezentanții pacienților cu SLOS în MetabERN, subrețeaua PD

#SE Swedish with English introduction

The heading in the box of the email to the organisations:

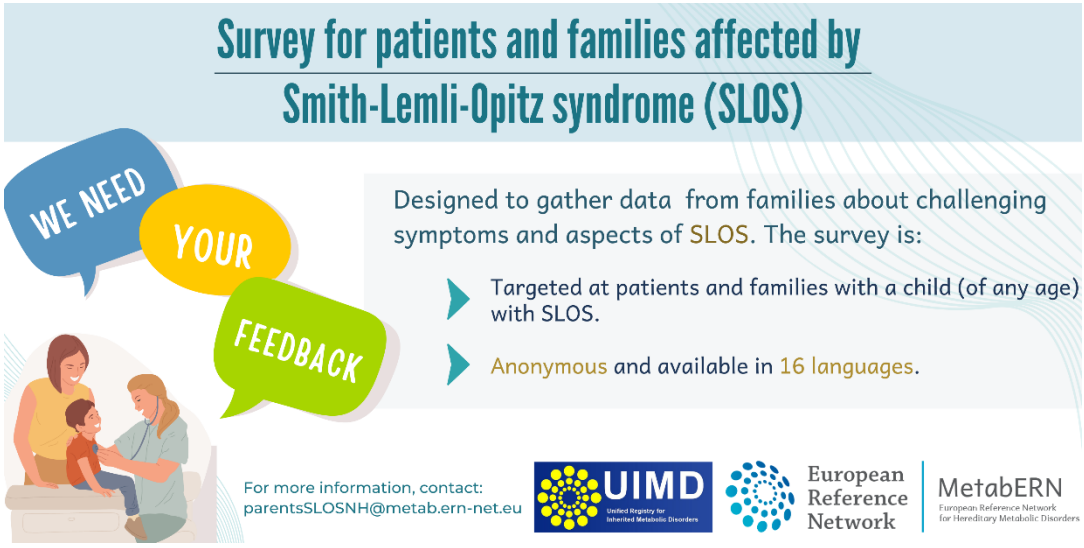
Ett nytt projekt för personer med Smith-Lemli-Opitz syndrom och deras familjer

Dear organisation,

We ask you to ***please forward this email with the enclosed letters*** to persons and families with children of all ages with Smith-Lemli-Opitz syndrome, SLOS. Answers from families who have lost one or more children due to SLOS are also very important to us. We appreciate if you disseminate this email to them as well.

We are patient representatives in MetabERN for persons with the rare inherited metabolic disorder Smith-Lemli-Opitz syndrome (SLOS). MetabERN is a European Reference Network on Hereditary Metabolic Disorders, established by the EU.

We have information about a new European project for persons with Smith-Lemli-Opitz syndrome and their families, the SLOS Natural History project. *More details are given in the enclosed letter* ***in Swedish*** *to the families.*



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Brief information about SLOS
SLOS is a metabolic disorder. The cause is an error in the synthesis of cholesterol in the body. That affects several biochemical processes in a complex way. Mildly affected persons may have no or minor inborn signs, near-normal cognitive function but often behavioural problems. A more severe impact of SLOS can be life threatening and involve malformations of many organs.

Karin Mossler, Antje Enekwe and Anne Kalweit,
Patient representatives in MetabERN for Smith-Lemli-Opitz syndrome.

SE Svenska
Ett nytt projekt för personer med Smith-Lemli-Opitz syndrom och deras familjer

Kära familj med barn (oavsett ålder) med Smith-Lemli-Opitz syndrom,

Vi vill informera er om ett nytt projekt för personer med Smith-Lemli-Opitz syndrom (SLOS): ***the SLOS Natural History project***, på svenska projektet Naturalförlopp vid SLOS.

Vi är patientrepresentanter i MetabERN för personer med SLOS. MetabERN är ett europeiskt referensnätverk för ärftliga metabola störningar som har inrättats av EU.

Förbättra rådgivning och utveckla terapier

Det nya projektet syftar till att förbättra rådgivningen till familjer och utarbeta strategier för behandling och långsiktig vård. Vanliga symptom och sällsynta tillstånd kommer att beskrivas, liksom hur vanligt det är med sömnstörningar, autism och komplexa beteenden som kan påverkar era familjer.

Vi hoppas att ni vill svara på en kort enkät (https://www.surveymonkey.com/r/28CNSVY) om vilka symptom och aspekter/konsekvenser av SLOS som ni anser vara viktiga och utmanande och om ni är intresserade av att få mer information om projektet eller gå med i ett familjenätverk. Det är också mycket viktigt för oss att få svar från familjer som förlorat ett eller flera barn på grund av SLOS, och vi uppskattar alla synpunkter.

Vi ser fram emot fortsatt kontakt!
E-postadress till oss: parentsSLOSNH@metab.ern-net.eu

Karin Mossler, Antje Enekwe och Anne Kalweit
Patientrepresentanter för SLOS i MetabERN, undernätverket PD (Peroxisomal and lipid related disorders, peroxisomala och fettämnesrelaterade sjukdomar)