Rapport Annuel
Annual Report
2022

BLACKSWAN®
FOUNDATION

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASE
SCHWEIZERISCHE STIFTUNG FÜR DIE FORSCHUNG SELTENER KRANKHEITEN
FONDATION SUISSE POUR LA RECHERCHE SUR LES MALADIES ORPHELINES
FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALATTIE ORFANE

TABLE DES MATIÈRE
TABLE OF CONTENTS

WE AMPLIFY COLLECTIVE ACTION FOR RESEARCH ON RARE DISEASES

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASES
SCHWEIZERISCHE STIFTUNG FÜR DIE FORSCHUNG SELTENER KRANKHEITEN
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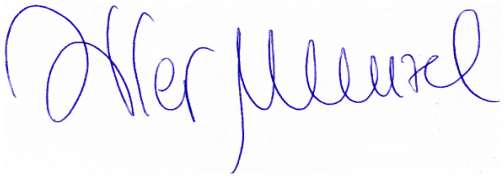
MESSAGE DU PRÉSIDENT

L'année 2022 est encore une année marquée par la pandémie, mais surtout par la guerre en Ukraine. Au moment où nous commencions à voir une lueur d'espoir concernant les levées de fonds, l'espace financier philanthropique s'est complétement, et à juste titre, focalisé sur l'aide aux victimes de guerre. Et malheureusement, ceci confirme mes craintes exprimées l'année précédant sur la possibilité de financer des projets de recherche ces prochaines années.

Cependant, l'année 2022 est aussi marquée par un soutien direct aux projets du RE(ACT) Discovery Institute, le premier institut qui soutient la recherche scientifique innovante dans le champ des maladies rares et répond aux besoins médicaux non satisfaits dans ce domaine. L'année 2022 a été aussi consacrée à l'organisation du RE(ACT) Congress 2023, qui aura finalement lieu en présentiel pour continuer à favoriser le réseautage parmi les scientifiques dédiés aux maladies rares dans le monde entier.

Encore une fois, je remercie du fond du cœur mes collègues au sein du conseil de Fondation pour leur travail et le développement de notre Fondation tout au long de cette année. Je suis sûr que le meilleur est à venir.



Dr. Olivier Menzel
Président et fondateur

"Nous travaillons dur pour tirer le meilleur parti de chaque centime investi dans la recherche!"

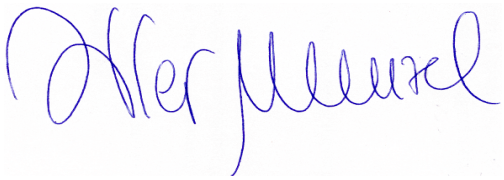
MESSAGE FROM THE PRESIDENT

The year 2022 is still marked by the pandemic, but above all, by the war in Ukraine. Just when we were beginning to see a glimmer of hope in fundraising, the philanthropic financial space became completely and rightly focused on helping the victims of war.

Unfortunately, this confirms my fears expressed last year about the possibility of funding research projects in the coming years.

However, 2022 is also marked by direct support for the projects of the RE(ACT) Discovery Institute, the first institute to support innovative scientific research in rare diseases and address unmet medical needs in this area.
The year 2022 was also dedicated to the organization of the RE(ACT) Congress 2023, which will finally take place face-to-face to continue fostering networking among rare disease scientists worldwide.

Once again, my heartfelt thanks go to my colleagues on the Foundation Board for their work and the development of our Foundation over the past year. I'm sure the best is yet to come.



Dr. Olivier Menzel
Chairman and Founder

"We are working hard to make the most of every cent invested in research!"

QU'EST-CE QU'UNE MALADIE RARE OU ORPHELINE?

En Suisse et dans l'Union européenne, une maladie est dite rare lorsque moins d'une personne sur 2'000 est atteinte, que la maladie est chronique et incapacitante et qu'un effort particulier doit être fourni pour développer un traitement. L'on retient aussi que les maladies rares réduisent souvent l'espérance de vie de qui en souffre.

Au niveau international, il n'y a pas de consensus autour du seuil d'incidence retenu pour définir la rareté. Aux États-Unis par exemple, il s'agit de toute pathologie ou condition de santé affectant moins d'une personne sur 1'500 (soit 200'000 personnes sur le territoire). L'on désigne par ailleurs une maladie comme orpheline lorsqu'il n'existe aucun traitement pour en venir à bout. Les médecins ne connaissent pas l'affection, la recherche et le diagnostic sont inexistants et les victimes, totalement délaissées du système sanitaire, souffrent d'un manque de reconnaissance quasi total.

Os de verre, syndrome du cri du chat, syndrome de Lowe… Les maladies rares et orphelines recouvrent une réalité très diversifiée. Elles peuvent empêcher de bouger (myopathies), de voir (rétinites), de comprendre (X fragile), de respirer (mucoviscidose), de résister aux infections (déficits immunitaires) etc. On en dénombre à ce jour au moins 8'000 dont le 80% au moins a une origine génétique. Il s'agit de pathologies infectieuses ou auto-immunes dans le 20% restant

UN PARCOURS DU COMBATTANT

Les enfants sont particulièrement concernés : trois malades sur quatre ont moins de dix-huit ans, et les maladies rares sont spécialement mortelles et incapacitantes dans leur cas. Ce alors que le corps médical peine souvent à établir un diagnostic de par le faible nombre de personnes touchées.
Outre la difficulté à se faire reconnaître et une espérance de vie réduite, les malades souffrent de handicaps à l'origine de discrimination et d'isolement. Il existe heureusement des associations pour leur venir en aide ainsi qu'à leurs proches.

WHAT IS A RARE OR ORPHAN DISEASE?

A disease or disorder is defined as rare in Europe and Switzerland when it affects not more than 1 in every 2,000 persons. These conditions are generally chronic, progressive, debilitating, and often life-threatening. In addition, these rare diseases present specific challenges for the development of new treatments.

There is no internationally accepted definition of rare diseases. For example, in the United States, a condition is rare when it affects 1 in every 1,500 persons (or less than 200,000 citizens). Furthermore, it is considered orphan any rare disease for which no treatment has been developed. Practitioners do not know the condition, research is not ongoing, and it is extremely difficult to receive a diagnosis for lack of scientific knowledge. For these reasons, patients feel abandoned by the health system and suffer from an almost total lack of care.

Osteogenesis imperfecta, Lowe syndrome, cri-du-chat syndrome…rare, and orphan diseases are a very diverse reality. These may affect one's ability to move (myopathies), to comprehend the world around us (fragile X syndrome), to breathe (cystic fibrosis), or to combat infection (immune deficiencies). It is estimated that there are at least 8,000 orphan diseases today, 80% of them are genetic in origin. The remaining 20% are autoimmune and infectious disorders.

A REAL STRUGGLE

Children are particularly concerned by rare diseases: three out of four patients are under the age of eighteen. In their case, rare diseases are particularly life-threatening and disabling, and medical professionals struggle to make a diagnosis because of the small number of people affected.
In addition to the difficulty in obtaining recognition and to a reduced life expectancy, patients suffer from disabilities that lead to discrimination and isolation. Fortunately, some associations help them, their families, and loved ones.

LA RECHERCHE SUR LES MALADIES RARES SE HEURTE À PLUSIEURS DIFFICULTÉS

> Des obstacles d'ordre scientifique: le faible nombre de malades recensés ne permet souvent pas de valider scientifiquement les résultats du travail de recherche, ce qui empêche la publication d'articles qui pourraient mobiliser l'attention et l'intérêt de la communauté des chercheurs;

> Des obstacles d'ordre financier: les agences nationales de financement public ne sont pas proactives dans le soutien de la recherche à cause du manque d'expertise des commissions internationales d'évaluation des projets et du nombre restreint de publications scientifiques de la part des chercheurs demandant un financement.

> Des obstacles d'ordre commercial: ces pathologies touchant un nombre très restreint de personnes, les grandes firmes pharmaceutiques négligent d'investir des moyens dans le développement de médicaments.

La recherche sur les maladies rares et orphelines présente pourtant un intérêt majeur, car elles peuvent servir de modèles pour des affections plus communes et aider à développer des médicaments efficaces à plus large échelle.

On l'a vu dans le cas de la leucémie, maladie qui est devenue chronique plutôt que mortelle grâce au développement par une grande firme pharmaceutique d'un médicament conçu à la base pour soigner une forme de leucémie rare des enfants, réfractaire aux médicaments à l'époque sur le marché. Par ailleurs, certaines start-ups ou entreprises se sont spécialisées dans la vente de médicaments pour les maladies rares et leur business model, bien que marginal, a prouvé qu'il fonctionnait.

Pour relever le défi de la recherche, il est cependant nécessaire que les spécialistes puissent échanger autour de compétences pluridisciplinaires et de bonnes pratiques, et que le plus grand nombre de patients participent à la recherche. Il s'agit aussi de renforcer les liens entre le monde académique et l'industrie pour que celle-ci puisse concrétiser les résultats obtenus en nouveaux outils diagnostiques et thérapeutiques.

RESEARCH ON RARE DISEASES FACES SEVERAL MAJOR CHALLENGES

> Scientific obstacles: the small number of patients often does not allow to scientifically validate the results of the research work, which prevents the publication of articles that could mobilize the attention and interest of the research community;

> Financial barriers: National public funding agencies are not proactive in supporting research because of the lack of expertise of international project assessment boards and of the limited number of scientific publications by researchers requesting funding.

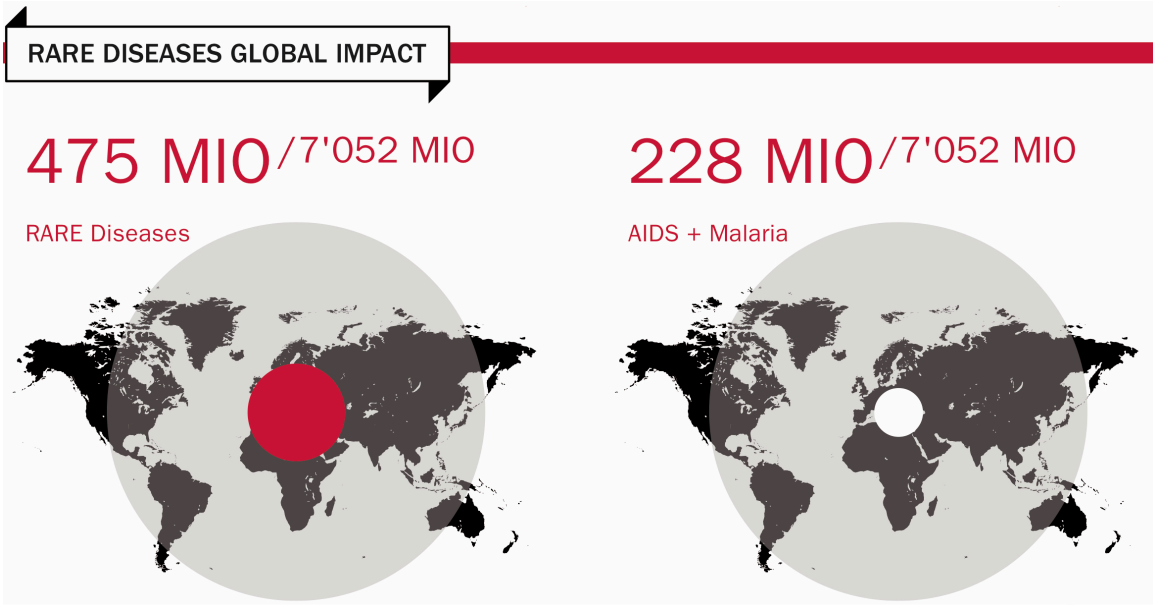
> Commercial obstacles: these diseases are affecting a minimal amount of people are often neglected by large pharmaceutical companies that are reticent to invest resources in the development of medicines.

Research on rare and orphan diseases is of considerable importance as it can serve as a model
for more common diseases and help develop effective drugs on a larger scale.

For example, in the case of leukemia: when a large pharmaceutical company developed a drug designed at the base to cure a rare pediatric form of leukemia that was resistant to the drugs available at the time on the market. This drug then revealed to be effective at fighting off all types of leukemia.

In recent years, some start-ups and companies specialized in the development of drugs for rare diseases, and their business model proved to be effective.

To meet the challenge of research, however, it is necessary for specialists to exchange best practices and use collaborative models and that the most significant number of patients participate in research. There is a need to strengthen partnerships between the academic world and the industry to obtain new diagnostic and therapeutic tools.



LA FONDATION

LA FONDATION EN BREF

Les maladies rares affectent 6 à 8% de la population mondiale et quelque 500'000 personnes en Suisse. Lorsqu'il s'agit d'enfants – dans trois cas sur quatre – l'issue est très souvent fatale. La quête de médicaments adaptés est donc une priorité, d'autant que leur efficacité a été démontrée dans le traitement de pathologies plus fréquentes.

La Fondation BLACKSWAN a été créée en Suisse en 2010 pour aider partout dans le monde celles et ceux qui sont impliqués dans ce combat. Elle soutient la recherche sur tout type de maladie rare ou orpheline, ce qui la rend unique au monde.

Outre son travail dans la quête de fonds, elle organise chaque deux ans un congrès appelé RE(ACT) Congress, devenu une référence internationale. En six éditions, plus de 1700 scientifiques ont pu mettre en place une cinquantaine de collaborations. Enfin, la Fondation mène depuis 2015 une campagne appelée #RAREvolution afin que les maladies rares deviennent une priorité de la recherche et de la santé publique.

THE FOUNDATION

THE FOUNDATION IN BRIEF

Rare diseases affect 6% to 8% of the world population and approximately 500,000 people in Switzerland. The majority of these conditions affect children, and in three out of four cases, have a fatal outcome. The quest for specific drugs is a priority, especially as the effectiveness of certain rare disease drugs has been demonstrated in the treatment of most common diseases.

The BLACKSWAN Foundation was established in Switzerland in 2010 to contribute to the development of research on rare and orphan diseases worldwide. The Foundation supports research on all different types of rare and orphan diseases, making its vision unique and finding new solutions that can assist a large variety of projects.

Besides its funding research mission, the Foundation organizes the RE(ACT) Congress every two years, which became an international reference point for rare disease experts. In six editions, more than 1,700 scientists were able to establish approximately fifty collaborations. Since 2015, BLACKSWAN Foundation has also started an international advocacy and awareness campaign called #RAREvolution to ensure rare diseases are recognized as a global public health and research priority.

1 338 612 968 **CHINA POPULATION**

1 156 897 766 **INDIA POPULATION**

475 304 355 **RARE DISEASE POPULATION**

302 074 000 **USA POPULATION**

2022 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

ONLY IN ENGLISH

RE(ACT) DICOVERY INSTITUTE

The majority of 2022 support went to the activities of the RE(ACT) Discovery Institute

The RE(ACT) Discovery Institute is a unique, not-for-profit institute that supports innovative scientific research in the field of rare diseases and addresses unmet medical needs in this area. An offshoot of the BLACKSWAN Foundation, a Swiss foundation active worldwide in supporting rare disease research, advocacy, and building an international scientific community.

The main pathology the RD-Institute addressed in 2022 is Duchenne Muscular Dystrophy (DMD), which affects 7,1 subjects in 100,000 males worldwide. There is no standard of care that allows a significant quality of life improvement, and patients witness progressive muscular degeneration that makes them lose their main functions early in their teenage years.

The RE(ACT) Discovery Institute (RD-Institute) aims to fund a study of drug repurposing after clinical and pharmacological preliminary encouraging results to bring an innovative formulation to market and make it available for pediatric patients.

The support needed for CHF is 850.000-. It would be mainly philanthropic support and would allow us to set up the trial with contract manufacturing partners, hospitals, research centers, and regulatory personnel. This would be a crucial milestone in the treatment and prevention of complications of DMD.

In parallel with fundraising activities, the project manager at the RD-Institute, Valeria Botti, conducted a review of tamoxifen as a potential therapeutic for Duchenne muscular dystrophy, which has been published in an important scientific journal.

frontiers in Pharmacology

Front Pharmacol. 2022; 13: 1030785.
Published online 2022 Nov 16. doi: 10.3389/fphar.2022.1030785
PMCID: PMC9709317
PMID: 36467064

A state-of-the-art review of tamoxifen as a potential therapeutic for duchenne muscular dystrophy

Valeria Botti, [1] Olivier Menzel,[✉1,*] and Davide Staedler [1,2,*]

Author information ▸ Article notes ▸ Copyright and License information PMC Disclaimer

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This article was submitted to Translational Pharmacology, a section of the journal Frontiers in Pharmacology

Abstract Go to: ▸

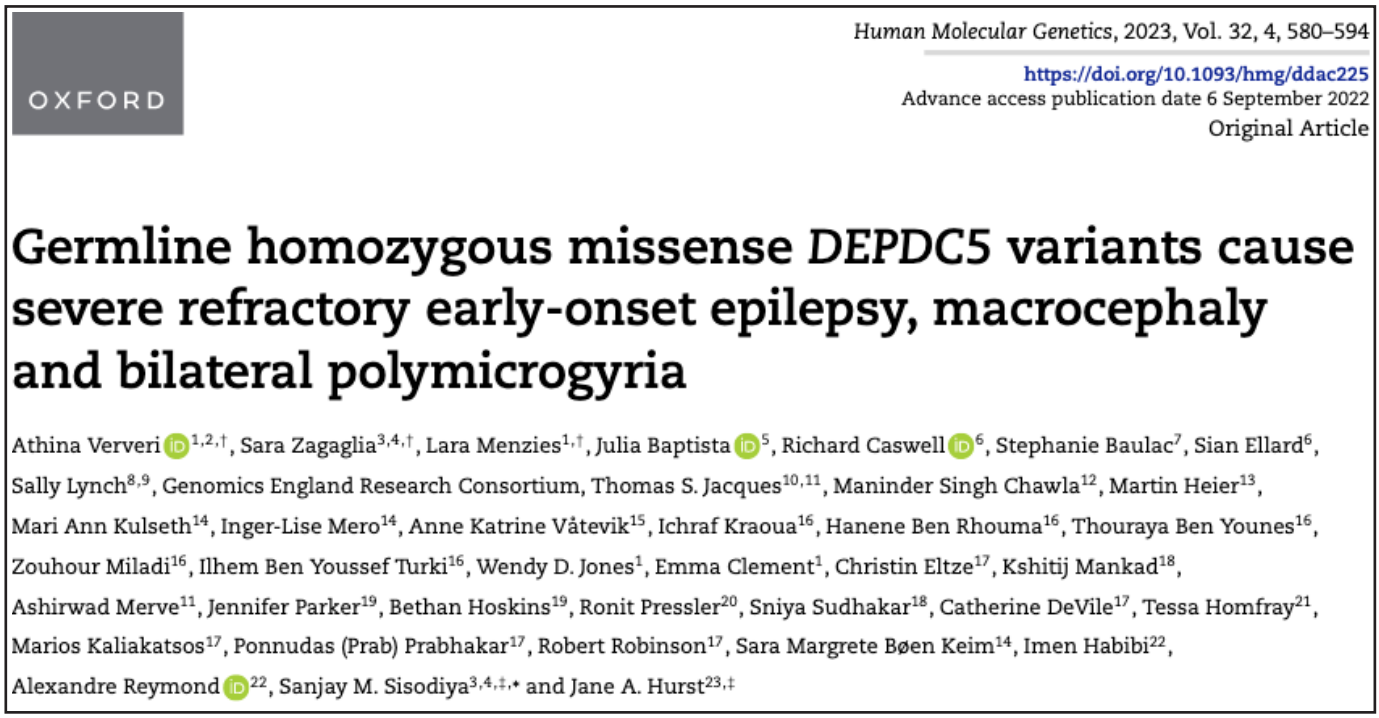
Introduction: This systematic review analyzes the state-of-art repurposing of the drug tamoxifen (TAM) in the treatment of Duchenne Muscular Dystrophy (DMD), including its mechanism of action, toxicological findings, and past and ongoing clinical trials. A parallel aim of this work was to explore whether evidence exists to support further funding of investigation on TAM treatment for DMD patients with a pivotal trial in young patients. Bringing evidence and answering the scientific question of whether this treatment could improve the quality-of-life of DMD patients is needed to establish guidelines and accelerate access to promising therapies for DMD patients.

2022 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

SEQUENCING OF 18 CONSANGUINEOUS MULTIPLEX PAKISTANI FAMILIES

To Professor Alexandre Reymond, Center for Integrative Genomics, University of Lausanne

This support resulted in three publications, and two other manuscripts will be submitted in 2023 on two more autosomal recessive genes, BRF2 and AFF3. Of note, the abstracts describing Prof. Reymond's findings were selected for platform presentations at the European Society of Human Genetics 2023 conference in Glasgow and the American Society of Human Genetics meeting in Washington, DC, respectively.

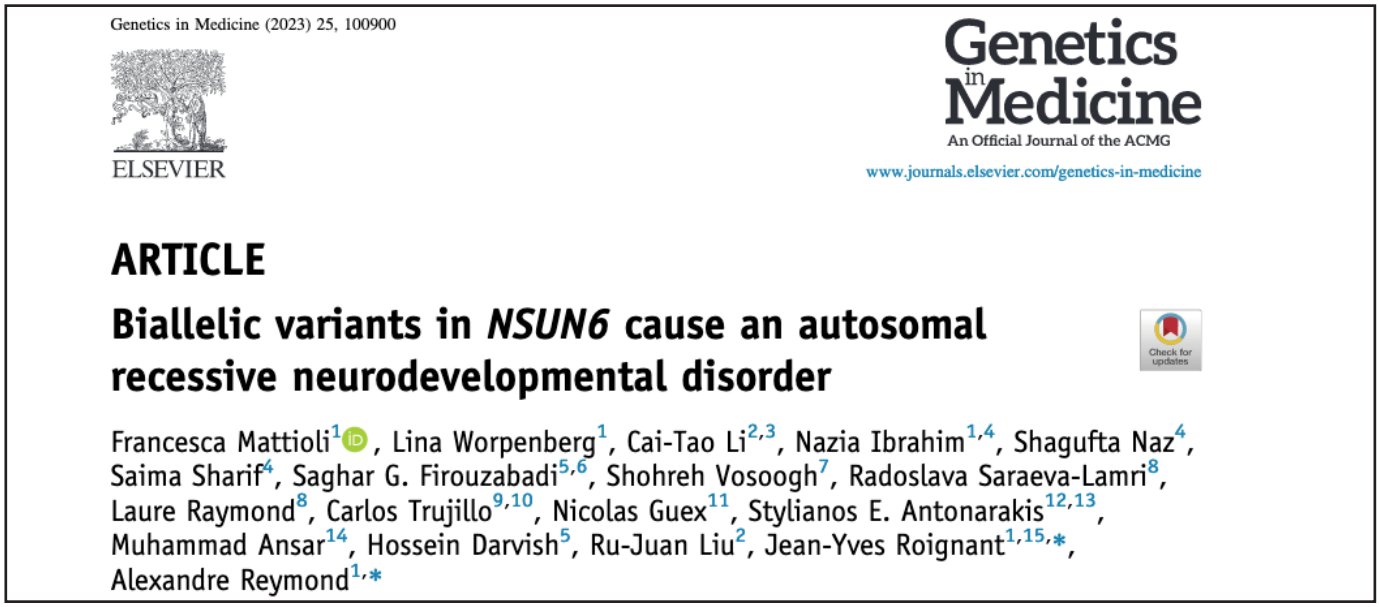


OXFORD

Human Molecular Genetics, 2023, Vol. 32, 4, 580–594
https://doi.org/10.1093/hmg/ddac225
Advance access publication date 6 September 2022
Original Article

Germline homozygous missense *DEPDC5* variants cause severe refractory early-onset epilepsy, macrocephaly and bilateral polymicrogyria

Athina Ververi[1,2,†], Sara Zagaglia[3,4,†], Lara Menzies[1,†], Julia Baptista[5], Richard Caswell[6], Stephanie Baulac[7], Sian Ellard[6], Sally Lynch[8,9], Genomics England Research Consortium, Thomas S. Jacques[10,11], Maninder Singh Chawla[12], Martin Heier[13], Mari Ann Kulseth[14], Inger-Lise Mero[14], Anne Katrine Våtevik[15], Ichraf Kraoua[16], Hanene Ben Rhouma[16], Thouraya Ben Younes[16], Zouhour Miladi[16], Ilhem Ben Youssef Turki[16], Wendy D. Jones[1], Emma Clement[1], Christin Eltze[17], Kshitij Mankad[18], Ashirwad Merve[11], Jennifer Parker[19], Bethan Hoskins[19], Ronit Pressler[20], Sniya Sudhakar[18], Catherine DeVile[17], Tessa Homfray[21], Marios Kaliakatsos[17], Ponnudas (Prab) Prabhakar[17], Robert Robinson[17], Sara Margrete Bøen Keim[14], Imen Habibi[22], Alexandre Reymond[22], Sanjay M. Sisodiya[3,4,‡,*] and Jane A. Hurst[23,‡]



Genetics in Medicine (2023) 25, 100900

ELSEVIER

Genetics in Medicine
An Official Journal of the ACMG
www.journals.elsevier.com/genetics-in-medicine

ARTICLE

Biallelic variants in *NSUN6* cause an autosomal recessive neurodevelopmental disorder

Francesca Mattioli[1], Lina Worpenberg[1], Cai-Tao Li[2,3], Nazia Ibrahim[1,4], Shagufta Naz[4], Saima Sharif[4], Saghar G. Firouzabadi[5,6], Shohreh Vosoogh[7], Radoslava Saraeva-Lamri[8], Laure Raymond[8], Carlos Trujillo[9,10], Nicolas Guex[11], Stylianos E. Antonarakis[12,13], Muhammad Ansar[14], Hossein Darvish[5], Ru-Juan Liu[2], Jean-Yves Roignant[1,15,*], Alexandre Reymond[1,*]

2022 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

Am J Hum Genet. 2023 Feb 2; 110(2): 215–227.
Published online 2022 Dec 30. doi: 10.1016/j.ajhg.2022.12.007
PMCID: PMC9943726
PMID: 36586412

Deleterious, protein-altering variants in the transcriptional coregulator *ZMYM3* in 27 individuals with a neurodevelopmental delay phenotype

Susan M. Hiatt,[1,*] Slavica Trajkova,[2] Matteo Rossi Sebastiano,[3] E. Christopher Partridge,[1] Fatima E. Abidi,[4] Ashlyn Anderson,[1] Muhammad Ansar,[5,49] Stylianos E. Antonarakis,[6] Azadeh Azadi,[7] Ruxandra Bachmann-Gagescu,[8] Andrea Bartuli,[9] Caroline Benech,[10] Jennifer L. Berkowitz,[11] Michael J. Betti,[12] Alfredo Brusco,[2] Ashley Cannon,[13] Giulia Caron,[3] Yanmin Chen,[11] Meagan E. Cochran,[1] Tanner F. Coleman,[1] Molly M. Crenshaw,[14] Laurence Cuisset,[15] Cynthia J. Curry,[16] Hossein Darvish,[17,18] Serwet Demirdas,[19] Maria Descartes,[13] Jessica Douglas,[20] David A. Dyment,[21] Houda Zghal Elloumi,[11] Giuseppe Ermondi,[3] Marie Faoucher,[22,23] Emily G. Farrow,[24] Stephanie A. Felker,[1] Heather Fisher,[25] Anna C.E. Hurst,[13] Pascal Joset,[26] Melissa A. Kelly,[27] Stanislav Kmoch,[28] Benjamin R. Leadem,[11] Michael J. Lyons,[4] Marina Macchiaiolo,[9] Martin Magner,[29] Giorgia Mandrile,[30] Francesca Mattioli,[31] Megan McEown,[1] Sarah K. Meadows,[1] Livija Medne,[32] Naomi J.L. Meeks,[33] Sarah Montgomery,[34] Melanie P. Napier,[11] Marvin Natowicz,[35] Kimberly M. Newberry,[1] Marcello Niceta,[9] Lenka Noskova,[28] Catherine B. Nowak,[20] Amanda G. Noyes,[11] Matthew Osmond,[21] Eloise J. Prijoles,[4] Jada Pugh,[1] Verdiana Pullano,[2] Chloé Quélin,[36] Simin Rahimi-Aliabadi,[37] Anita Rauch,[8,38] Sylvia Redon,[10,39,40] Alexandre Reymond,[31] Caitlin R. Schwager,[41] Elizabeth A. Sellars,[42] Angela E. Scheuerle,[43] Elena Shukarova-Angelovska,[44] Cara Skraban,[32] Elliot Stolerman,[4] Bonnie R. Sullivan,[41] Marco Tartaglia,[9] Isabelle Thiffault,[24] Kevin Uguen,[10,39,40] Luis A. Umaña,[43] Yolande van Bever,[19] Saskia N. van der Crabben,[45] Marjon A. van Slegtenhorst,[19] Quinten Waisfisz,[46,47] Camerun Washington,[4] Lance H. Rodan,[20,48] Richard M. Myers,[1] and Gregory M. Cooper[1,**]

2022 ACTIVITIES
INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

Due to the post COVID-19 outbreak, and the war of aggression against Ukraine it has been not possible to organize any event to increase awareness and collect funds.

FINANCIAL REPORT 2022

BLACKSWAN FDN. FOR RES. ON ORPH. DIS. - PORZA List Printed on 19 giugno 2023 14:2

Balance to 31.12.2022
Metodo del costo complessivo

Account No		Account Name	Balance CHF	Prev. FY CHF	
Assets					
Current assets					
Cash and bank accounts					
1020		Bank account Raiffeisen CHF	21'751.13	2'488.19	874.17
1021	EUR	Bank account Raiffeisen EUR	19'592.90	71'027.52	27.58
1022	USD	Bank account Raiffeisen USD	133.38	18'436.18	0.72
Total Cash and bank accounts			41'477.41	91'951.89	45.11
Accruals					
1300		Accruals and prepaid expenses		100.00	0.00
Total Accruals				100.00	0.00
Total Current assets			**41'477.41**	**92'051.89**	45.06
Fixed assets					

FINANCIAL REPORT 2022

BLACKSWAN FDN. FOR RES. ON ORPH. DIS. - PORZA

List Printed on 19 giugno 2023 14:27

Balance to 31.12.2022
Metodo del costo complessivo

Account No	Account Name	Balance CHF	Prev. FY CHF	
Liabilities				
Current liabilities				
Short-term third party capital				
Accounts payable				
2004	Other debts		-3'231.00	0.00
Total Accounts payable			-3'231.00	0.00
Accruals				
2300	Accrued expenses	-2'154.00	-2'154.00	100.00 +
Total Accruals		-2'154.00	-2'154.00	100.00 +
Total Short-term third party capital		**-2'154.00**	**-5'385.00**	40.00 +
Total Current liabilities		**-2'154.00**	**-5'385.00**	40.00 +
Foundation equity				
Reserves/Profit or Loss of financial year				
2970	Profit/Loss account	-107'046.89	-114'394.35	93.58 +
Total Reserves/Profit or Loss of financial year		-107'046.89	-114'394.35	93.58 +
Total Foundation equity		**-107'046.89**	**-114'394.35**	93.58 +
Total Liabilities		**-109'200.89**	**-119'779.35**	91.17 +
Loss		-47'443.48	-7'347.46	645.71 -
TOTAL DR/CR		**61'757.41**	**112'431.89**	

FINANCIAL REPORT
2022 PROFIT & LOSS

BLACKSWAN FDN. FOR RES. ON ORPH. DIS. - PORZA

List Printed on 19 giugno 2023 14:27

Profit and Loss from 01.01.2022 to 31.12.2022

Metodo del costo complessivo

Account No	Account Name	Balance CHF	Prev. FY CHF	
Profit & Loss statement				
3000	Revenues from donations, offers	33'371.08	16'295.00	204.79 +
+ Net revenues from supplies and services		33'371.08	16'295.00	204.79 +
= Revenues from supplies and services		**33'371.08**	**16'295.00**	204.79 +
4000	Support for projects and research	70'500.00		100.00
- Costs for material, goods, services and energy		70'500.00		100.00
= Gross operating result after deducting costs for materials and goods		**-37'128.92**	**16'295.00**	227.85 -
6361	Taxes	200.00	469.29	42.62 +
6501	Print		1'887.65	0.00
6530	Accounting costs	5'385.00	5'956.86	90.40 +
6559	Other administration costs		1'760.00	0.00
6584	IT costs	3'082.55	1'371.50	224.76 +
6640	Travel expenses	705.00	1'605.80	43.90 +
6673	Conventions expenses		3'103.76	0.00
- Other operating expenses		9'372.55	16'154.86	58.02 +
= Operating result before depreciation and value adjustments, financial results and taxes (EBITDA)		**-46'501.47**	**140.14**	33'182.15 -
6821	Depreciation office furniture	100.00	130.00	76.92 +
6822	Depreciation information technology		761.55	0.00
- Depreciation and value adjustments of fixed assets		100.00	891.55	11.22 +
= Operating result before financial results and taxes (EBIT)		**-46'601.47**	**-751.41**	6'201.87 +
6940	Bank charges	274.24	958.91	28.60 +
6947	Exchange loss USD		1'282.62	0.00
6949	Exchange loss EUR	1'554.21	5'377.15	28.90 +
- Financial costs		1'828.45	7'618.68	24.00 +
6997	Exchange gain USD	447.94		100.00
+ Financial revenues		447.94		100.00
= Operating result before taxes (EBT)		**-47'981.98**	**-8'370.09**	573.26 +
8709	Extraordinary costs to other acc.periods		-331.70	0.00
+ Extraordinary or unique costs for other accounts periods			-331.70	0.00
8719	Extraordinary revenue to other acc.periods	538.50	1'354.33	39.76 +
+ Extraordinary or unique revenues for other accounts periods		538.50	1'354.33	39.76 +
= Profit or loss before taxes		**-47'443.48**	**-7'347.46**	645.71 +

NOTES TO FINANCIAL STATMENTS

NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2022

1. ORGANIZATION

The BLACKSWAN Foundation (BSF) is a Swiss Foundation, established as a not-for-profit legal entity registered in Porza under statutes dated 15th April 2010 and in accordance with article 80 and those that follow of the Swiss Civil Code. It is managed by a foundation board. BSF contributes to the development of research on rare and orphan diseases worldwide. The Foundation supports research on all different types of rare and orphan disease, which makes its vision unique and helps in finding new solutions that can assist a large variety of projects.
As with all Swiss foundations recognized for international public good, BSF is monitored by the Swiss Federal Supervisory Board for Foundations.
The capital fund is fully subscribed at CHF 50,000 as stipulated under the original legal statutes of BLACKSWAN Foundation.

2. GOVERNANCE

The Foundation Board is the Foundation's supreme body. It takes all decisions necessary or effective for the achievement of the Foundation's aims. It has general responsibility for the affairs of the Foundation and supervises all activities carried out under its authority by the Foundation's other bodies to which power and authority have been delegated.
Members of the Board act on voluntary basis and may not claim any financial compensation other than expenses incurred such as travel and accommodation. For activities over and above the normal requirements of the position, each Member may receive appropriate reimbursement and compensation. Payment of any such reimbursement or compensation is only permissible where it corresponds to a service carried out of for the benefit of the Foundation.

3. RECOGNITION OF DONATIONS

Contribution from donors (public, private and philanthropic sources) are recognised in the financial statement on an accrual basis when they have been received or confirmed in writing pledges. Contributions which are subject to donor-imposed stipulation for a specific purpose or use in future years may be deferred or attributed to a restricted reserve according to the particular nature of the specific conditions.

BLACKSWAN FOUNDATION - FOR RESEARCH ON ORPHAN DISEASES 6948 PORZA

NOTES TO THE FINANCIAL STATEMENT AT 31.12.2022 (art. 959c CO)

General
The foundation BLACKSWAN FOUNDATION - FOR RESEARCH ON ORPHAN DISEASES was registered on 15.04.2010. Its activities comprise a therapeutic research for rare or orphan diseases due to the lack of financial support often encountered by public research laboratories on rare or orphan diseases.

Principles applied in these financial statements
The annual financial statements have been prepared in compliance with the principles established by the Swiss Code of Obligations, valid from 01.01.2015.

1. **Name, legal form and location**
   BLACKSWAN FOUNDATION - FOR RESEARCH ON ORPHAN DISEASES
   Via Cantonale 26
   6948 Porza
2. **Average annual full time job positions**
   No employees.
3. **Participation in other companies**
   RE(ACT) DISCOVERY INSTITUTE SARL
   Route de la Corniche 5
   1066 Epalinges
4. **Shares and holdings in other companies**
   RE(ACT) DISCOVERY INSTITUTE SARL - Participation 100%.
5. **Disposals**
   Not applicable.
6. **Leases liabilities**
   Not applicable.
7. **Pension plans debts**
   Not applicable.
8. **Guarantees**
   Not applicable.
9. **Assets and guarantees**
   Not applicable.
10. **Legal commitments**
    Not applicable.
11. **Rights and options**
    Not applicable.
12. **Extraordinary or non-recurring income/expenses, or income/expenses relating to other periods**
    These are amounts relating to adjustments of previous years.

BLACKSWAN FOUNDATION - FOR RESEARCH ON ORPHAN DISEASES 6948 PORZA

NOTES TO THE FINANCIAL STATEMENT AT 31.12.2022 (art. 959c CO)

13. **Subsequent events**
    None.
14. **Audit office, possible resignation**
    None.
15. **Other informations prescribed by law**
    None.

**BLACKSWAN FOUNDATION -
FOR RESEARCH ON ORPHAN DISEASES**

BLACKSWAN FOUNDATION AFFILIATIONS & PARTNERS

- ProRaris - Swiss rare disease alliance - www.proraris.ch
- EURORDIS - European alliance of patient organizations - www.eurordis.org
- E-RARE - European consortium of national funding bodies for research on rare diseases - www.erare.eu
- European Joint Programme on Rare Diseases - www.ejprarediseases.org
- RDI - Rare Disease International - The the global alliance of people living with a rare disease of all nationalities across all rare diseases - www.rarediseasesinternational.org

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Vuarrens, Switzerland

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Swiss Agency for Development and Coopertion
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University of Adelaide, Australia
Prof. ETIENNE SOKAL MD;
Head of the Pediatric Gastroenterology-Hepatology Unit, Catholic University of Leuven, Belgium

DONATIONS

ONLINE
www.blackswanfoundation.ch
(secured payment by credit card or PayPal)

BY BANK TRANSFER
Banca Raiffeisen del Cassarate
Piazza Motta, 6950 Tesserete
Switzerland

Donation in CHF:
IBAN: CH74 8080 8008 1468 1323 8

Donation in Euro:
IBAN: CH12 8080 8009 4017 8357 3

Donation in USD:
IBAN: CH41 8080 8001 0905 5135 4

SWIFT: RAIFCH22XXX

CONTACT

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1418 Vuarrens - Switzerland
Infoline: +41 21 887 64 34
contact@blackswanfoundation.ch

www.blackswanfoundation.ch
www.react-congress.org

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BLACKSWAN®
FOUNDATION

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASE
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FONDATION SUISSE POUR LA RECHERCHE SUR LES MALADIES ORPHELINES
FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALATTIE ORFANE