

Rapport Annuel

Annual Report

2025

BLACKSWAN[®]
FOUNDATION

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASE
SCHWEIZERISCHE STIFTUNG FÜR DIE FORSCHUNG BEI ERBEN KRAUKHEITEN
FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALADIE ORFANE

TABLE DES MATIÈRES

TABLE OF CONTENTS

Message du président.....4

Message from the president5

Qu'est-ce qu'une maladie rare ou orpheline..... 6

About rare and orphan diseases.....7

La recherche sur les maladies rares se heurte à plusieurs difficultés majeures..... 8

Research on rare diseases faces several major challenges..... 9

La Fondation en bref.....10

The foundation in brief.....11

2023 Activities..... 12

Support for scientific research..... 12

Financial report 2025.....15

Affiliations and partnerships..... 22

Members of the Foundation..... 23

Contact, links and donation information..... 24

**WE
AMPLIFY
COLLECTIVE
ACTION FOR
RESEARCH ON
RARE DISEASES**

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

MESSAGE DU PRÉSIDENT

En 2025, la Fondation a soufflé ses quinze bougies. Quinze années passées à défendre une conviction simple : aucune maladie ne devrait être laissée de côté au seul motif qu'elle est rare.

Le contexte, lui, ne s'est guère éclairci. La prudence qui s'est emparée du monde philanthropique ces dernières années perdure, et les moyens disponibles pour la recherche fondamentale sur les maladies rares restent très en deçà des besoins. Le RE(ACT) Discovery Institute demeure en pause, et je ne vous cacherai pas que cette situation continue de me préoccuper.

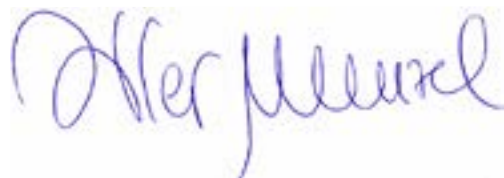
Et pourtant, 2025 restera une année importante. En mars, le congrès RE(ACT) a tenu sa huitième édition à Bruxelles, conjointement avec la conférence de l'IRDiRC et, pour la première fois, avec la toute nouvelle Alliance européenne pour la recherche sur les maladies rares (ERDERA). Voir cette plateforme, née en 2012 d'une intuition suisse, devenir le point de rencontre entre la communauté internationale et les institutions européennes est une source de fierté considérable.

Surtout, la Fondation s'est engagée cette année aux côtés d'une équipe de l'University College London pour un programme de trois ans consacré aux ataxies cérébelleuses liées au gène ITPR1. C'est un engagement de recherche ambitieux, et il illustre exactement ce pour quoi nous existons : financer un travail exigeant, sur une maladie que presque personne ne finance, avec l'objectif explicite d'aboutir à un traitement.

Enfin, un mot sur la Suisse. En septembre 2025, le Conseil fédéral a chargé le Département fédéral de l'intérieur d'ouvrir une consultation sur un projet de loi relatif aux maladies rares. Après des années de plaidoyer collectif, c'est le signal que nous attendions.

Je remercie une fois encore, du fond du cœur, mes collègues du conseil de la Fondation pour leur engagement bénévole et constant. Quinze ans après, ma conviction n'a pas changé : le meilleur reste à venir.

Dr. Olivier Menzel
Président et fondateur



“Nous travaillons d’arrache-pied pour tirer le meilleur parti de chaque centime investi dans la recherche !”

MESSAGE FROM THE PRESIDENT

In 2025, the Foundation turned fifteen. Fifteen years spent defending a simple conviction: no disease should be left behind for the sole reason that it is rare.

The environment has hardly improved. The caution that has gripped the philanthropic world in recent years persists, and the resources available for fundamental research into rare diseases remain far below what is needed. The RE(ACT) Discovery Institute is still on hold, and I will not pretend that this does not continue to worry me.

And yet 2025 will remain an important year. In March, the RE(ACT) Congress held its eighth edition in Brussels, jointly with the IRDiRC Conference and, for the first time, with the newly established European Rare Diseases Research Alliance (ERDERA). Seeing this platform — born in 2012 from a Swiss intuition — become the meeting point for the international community and the European institutions is a considerable source of pride.

Above all, the Foundation committed this year to a three-year program with a team at University College London, dedicated to cerebellar ataxias caused by mutations in the ITPR1 gene. It is an ambitious research commitment, and it illustrates precisely why we exist: to fund demanding work on a disease almost nobody else funds, with the explicit aim of reaching a treatment.

A final word on Switzerland. In September 2025, the Federal Council instructed the Federal Department of Home Affairs to open a consultation on draft legislation dedicated to rare diseases. After years of collective advocacy, this is a signal we had been waiting for.

Once again, I would like to thank my colleagues on the Foundation Board most warmly for their voluntary and unwavering commitment. Fifteen years on, my conviction has not changed: 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. On retient également que les maladies rares réduisent souvent l'espérance de vie de leurs malades.

À l'échelle internationale, il n'existe pas de consensus quant au 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). On désigne par ailleurs une maladie comme orpheline lorsqu'aucun traitement n'existe pour en venir à bout. Les médecins ne connaissent pas l'affection, la recherche et le diagnostic sont inexistants, et les malades, délaissés par le système de santé, souffrent d'un manque quasi total de reconnaissance.

Os de verre, syndrome du cri du chat, syndrome de Lowe, ataxies cérébelleuses... 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 coordonner ses gestes (ataxies) ou de résister aux infections (déficits immunitaires). On en dénombre aujourd'hui entre 6'000 et 8'000, et ce nombre continue d'augmenter avec les progrès du diagnostic génétique. Au moins 80 % d'entre elles ont une origine génétique ; les 20 % restants sont des pathologies infectieuses, auto-immunes ou dégénératives.

UN PARCOURS DU COMBATTANT

Les enfants sont particulièrement concernés : trois malades sur quatre ont moins de dix-huit ans, et les maladies rares sont souvent mortelles ou incapacitantes chez eux. Le corps médical peine par ailleurs à établir un diagnostic, précisément en raison du faible nombre de personnes touchées : l'errance diagnostique se compte encore fréquemment en années.

Outre la difficulté à se faire reconnaître et une espérance de vie réduite, les malades souffrent de handicaps qui entraînent de la discrimination et de l'isolement. Heureusement, il existe des associations pour leur venir en aide, ainsi que pour leurs proches.

WHAT IS A RARE OR ORPHAN DISEASE ?

In Switzerland and the European Union, a disease is considered rare when it affects fewer than 1 in 2,000 people, is chronic and disabling, and requires a specific effort to develop a treatment. Rare diseases also frequently shorten the life expectancy of those affected.

There is no internationally agreed threshold for rarity. In the United States, for example, a condition is rare when it affects fewer than 1 in 1,500 people (or fewer than 200,000 citizens). A rare disease is further described as an orphan disease when no treatment exists. Practitioners are unfamiliar with the condition, research and diagnostic pathways are lacking, and patients — abandoned by the health system — suffer from an almost total lack of recognition.

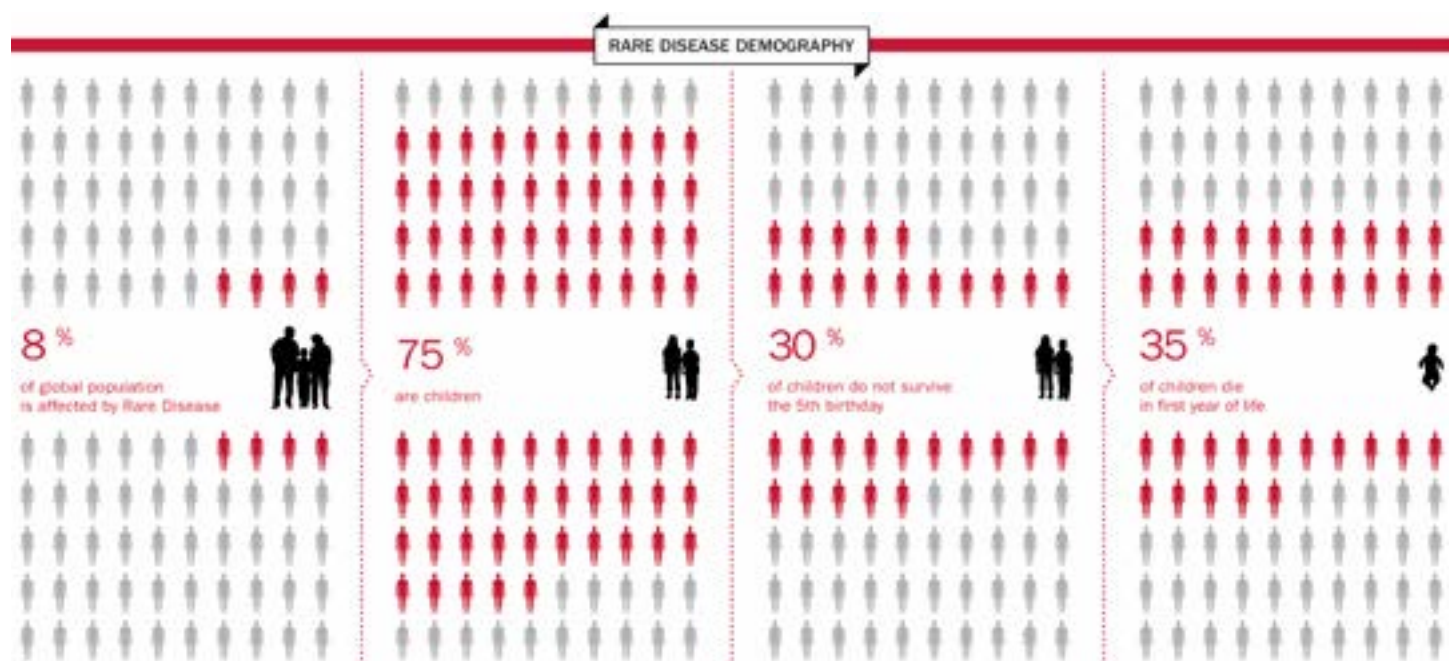
Osteogenesis imperfecta, cri du chat syndrome, Lowe syndrome, cerebellar ataxias... rare and orphan diseases encompass an extremely diverse spectrum. They may affect one's ability to move (myopathies), to see (retinitis), to understand the

world (fragile X syndrome), to breathe (cystic fibrosis), to coordinate movement (ataxias) or to fight infection (immune deficiencies). Between 6,000 and 8,000 are currently described, and that number continues to grow as genetic diagnosis improves. At least 80% are genetic in origin; the remaining 20% are infectious, autoimmune, or degenerative conditions.

A REAL STRUGGLE

Children are particularly affected: three out of four patients are under eighteen, and in their case rare diseases are frequently life-threatening or disabling. Medical professionals also struggle to reach a diagnosis, precisely because so few people are affected: the diagnostic odyssey is still commonly measured in years.

In addition to the difficulty of obtaining recognition and a reduced life expectancy, patients live with disabilities that lead to discrimination and isolation. Fortunately, associations exist to support them, their families, and their loved ones.



LA RECHERCHE SUR LES MALADIES RARES SE HEURTE À PLUSIEURS DIFFICULTÉS MAJEURES

> Des obstacles d'ordre scientifique : le faible nombre de malades recensés ne permet souvent pas de valider statistiquement les résultats de la recherche, ce qui empêche la publication d'articles susceptibles de mobiliser l'attention de la communauté scientifique.

> Des obstacles d'ordre financier : les agences nationales de financement public sont peu proactives, en raison du manque d'expertise des commissions d'évaluation sur ces pathologies et du nombre restreint de publications des chercheurs qui sollicitent un financement. Un cercle vicieux s'installe : pas de données, donc pas de financement ; pas de financement, donc pas de données.

> Des obstacles d'ordre commercial : ces pathologies touchant un nombre très restreint de personnes, l'industrie pharmaceutique hésite à investir dans le développement de médicaments.

> Un obstacle d'échelle : les modèles d'étude font souvent défaut. Pour de nombreuses maladies rares, il n'existe tout simplement pas de modèle cellulaire ou animal fiable permettant de comprendre le mécanisme de la maladie et d'y tester des traitements. Construire ces modèles est

long, coûteux, et rarement financé — alors que rien ne peut avancer sans eux.

La recherche sur les maladies rares et orphelines présente pourtant un intérêt majeur, car elle peut servir de modèle pour des affections plus répandues et aider à développer des médicaments efficaces à plus grande échelle.

On l'a vu dans le cas de la leucémie, devenue chronique et non plus mortelle grâce au développement, par une grande firme pharmaceutique, d'un médicament conçu à l'origine pour soigner une forme rare de leucémie de l'enfant, réfractaire aux traitements alors disponibles. Par ailleurs, certaines entreprises se sont spécialisées dans le développement de médicaments contre les maladies rares et ont démontré la viabilité de ce modèle d'affaires.

Pour relever ce défi, il faut que les spécialistes échangent sur des compétences pluridisciplinaires et de bonnes pratiques, que le plus grand nombre de patients participe à la recherche, et que les liens se renforcent entre le monde académique et l'industrie afin de traduire les résultats en outils diagnostiques et thérapeutiques concrets.

RESEARCH ON RARE DISEASES FACES SEVERAL MAJOR CHALLENGES

> Scientific obstacles: the small number of identified patients often makes it impossible to validate research findings statistically, which prevents the publication of articles capable of drawing the attention of the scientific community.

> Financial barriers: national public funding agencies are not proactive because assessment boards lack expertise in these conditions and because researchers applying for funding have few publications to show. A vicious circle sets in: no data, therefore no funding; no funding, therefore no data.

> Commercial obstacles: since these diseases affect very few people, the pharmaceutical industry is reluctant to invest in drug development.

> A problem of scale: research models are frequently missing altogether. For many rare diseases, there is simply no reliable cellular or animal model to understand the disease mechanism and test candidate treatments. Building

those models is slow, expensive, and rarely funded — yet nothing can move forward without them.

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

Leukemia is a case in point: a large pharmaceutical company developed a drug intended to treat a rare pediatric form of the disease that resisted the treatments then available. That drug later proved effective against other forms of leukemia. In recent years, several companies specializing in rare disease drugs have demonstrated that this business model can work.

To meet the challenge, specialists must share multidisciplinary expertise and best practices, ensure that as many patients as possible can participate in research, and strengthen partnerships between academia and industry so that results translate into concrete diagnostic and therapeutic tools.



LA FONDATION

LA FONDATION EN BREF

Les maladies rares affectent 6 à 8 % de la population mondiale et plus d'un demi-million de personnes en Suisse — soit davantage que le diabète. Dans trois cas sur quatre, il s'agit d'enfants, et l'issue est très souvent fatale. La recherche de médicaments adaptés est donc une priorité, d'autant que leur efficacité a été démontrée à plusieurs reprises 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 impliqués dans ce combat. Elle soutient la recherche sur tous les types de maladies rares ou orphelines, sans se limiter à une seule pathologie, ce qui la rend unique au monde.

Outre son travail de collecte de fonds et de financement de projets, elle organise tous les deux ans le RE(ACT) — Rare Disease Research Congress, devenu une référence internationale. En huit éditions, depuis 2012, ce congrès a réuni plusieurs milliers de scientifiques et permis la mise en place d'une cinquantaine de collaborations.

Enfin, la Fondation mène depuis 2015 la campagne #RAREvolution, afin que les maladies rares deviennent une priorité pour la recherche et la santé publique.

THE FOUNDATION

THE FOUNDATION IN BRIEF

Rare diseases affect 6 to 8% of the world population and more than half a million people in Switzerland — more than diabetes. In three out of four cases they affect children, and the outcome is very often fatal. The search for suitable medicines is therefore a priority, all the more so since their effectiveness has repeatedly been demonstrated in treating more common conditions.

The BLACKSWAN Foundation was established in Switzerland in 2010 to support, anywhere in the world, those engaged in this fight. It funds research into every type of rare and orphan disease rather than limiting itself to a single condition, which makes it unique.

Alongside its fundraising and grant-making mission, the Foundation organizes the RE(ACT) — Rare Disease Research Congress every two years, now an international reference point. Across eight editions since 2012, the congress has brought together several thousand scientists and given rise to some fifty collaborations.

Since 2015, the Foundation has also run the #RAREvolution international advocacy and awareness campaign to ensure that rare diseases are recognized as a global research and public health priority.



2025 ACTIVITIES SUPPORT FOR SCIENTIFIC RESEARCH

in English only

RE(ACT) - RARE DISEASE RESEARCH CONGRESS

5–7 March 2025 — Pullman Brussels Centre Midi,
Brussels, Belgium

The event was organized by the BLACKSWAN Foundation together with the International Rare Diseases Research Consortium (IRDiRC) and, for the first time, the European Rare Diseases Research Alliance (ERDERA) — the European partnership launched in late 2024, which brings together more than 180 organizations across 36 countries and succeeds the EJP RD. The congress was further supported by EURORDIS – Rare Diseases Europe and Rare Diseases International (RDI), with funding from the European Commission.

Over three days, more than 200 participants from 39 different countries- scientists, clinicians, patient advocates, funders, regulators, and policymakers worked through the field's most pressing questions.

The full list of speakers and panelists, and the abstract book, are available at <https://www.react-congress.org/2025/>.

KEY THEME

Accelerating diagnosis and data sharing

Newborn screening, in place since the 1960s, is being transformed by genomic techniques and machine learning, enabling faster, more precise detection of complex conditions. Speakers called for clearer and more consistent data policies, arguing that shared standards and platforms are what will turn diagnostic promise into diagnostic practice.

Advanced therapies: from mRNA to gene editing. Advanced Therapy Medicinal Products (ATMPs) were a major focus, with researchers presenting mRNA-based treatments and diagnostics as well as gene-editing approaches. Nick Sireau, CEO and Chair of

the AKU Society, described mRNA as a platform technology particularly well suited to monogenic diseases, where it can supply the code for a missing or malfunctioning enzyme. Participants also underlined the growing potential of drug repurposing, noting that recent regulatory changes can simplify trials and approvals, thereby speeding up patient access.

Societal impact.

Rare diseases affect not only individuals but families and entire support networks. From mental health to the need for flexible school policies, the congress emphasized that patient experience must guide reform. Sofie Skoubo, a PhD student at Aarhus University, Paralympian, and herself affected by a neuromuscular condition, argued that access to education gives people a voice and called for genuinely inclusive mainstream schooling.

Funding models.

Speakers pressed for faster, better-coordinated action and for new financing approaches. Irene Norstedt, Director at the European Commission's DG Research and Innovation, argued that traditional funding falls short for rare diseases because patient numbers are small while the scientific challenges are large, and advocated mixing models to pool industry resources, academic knowledge, and the expectations of patient organizations.

Closing remarks.

Organizers stressed that strong partnerships between public authorities, research institutions, patient advocacy groups and private actors accelerate progress in diagnostics and therapies. "Our strength lies in collaboration", said Daria Julkowska, ERDERA's Coordinator, whose goal is to turn promising advances into meaningful benefits for people living with these conditions.

2025 ACTIVITIES SUPPORT FOR SCIENTIFIC RESEARCH

in English only



More photos on Flickr: <https://www.flickr.com/photos/blackswanfoundation/albums/72177720324324941/>

2025 ACTIVITIES SUPPORT FOR SCIENTIFIC RESEARCH

SUPPORT TO PROF. FRANCESCO MUNTONI'S TEAM AT UNIVERSITY COLLEGE LONDON (UK) — QUEEN SQUARE INSTITUTE OF NEUROLOGY, GENE THERAPY ACCELERATOR CENTRE (GTAC)

Project title: Novel models and therapeutic approaches for *ITPR1*-related spinocerebellar ataxia

Team:

Project lead: Dr Ricardo Parolin-Schnekenberg, Research Fellow, GTAC.

Co-supervision: Prof. Francesco Muntoni (Director, GTAC) and Prof. Selina Wray (iPSC technology platform, UCL).

Duration:

3 years (2025–2028), starting August 2025

Amount:

GBP 805'771.61

Summary:

The ITPR1 gene encodes IP3R1, an intracellular calcium release channel that regulates calcium release from intracellular stores. Mutations in ITPR1 damage the cerebellum — and in particular its Purkinje cells — causing a group of conditions that includes spinocerebellar ataxia types 15 and 29 and Gillespie syndrome. Despite an extensive literature on the gene, it remains unclear how individual mutations translate into disease, and there is currently no treatment.

The project pursues four objectives: (1) to determine the functional consequences of the newly identified D34A mutation alongside four previously characterised variants, using calcium imaging in an engineered cell line; (2) to build human cerebellar organoids — “mini-cerebellums” containing functional Purkinje neurons — carrying ITPR1 mutations, in order to study the disease in the tissue that it actually affects; (3) to establish a simpler two-dimensional model of iPSC-derived sensory neurons, fast enough to allow iterative testing of candidate therapies; and (4) to develop and evaluate genetic therapies, alongside a high-throughput screen of approved drugs capable of increasing expression of the related ITPR2 and TPR genes — a strategy that, if successful, would be independent of the patient's specific mutation.

The program is structured in six work packages with formal milestones and go/no-go decision points at months 12, 24 and 36.

FINANCIAL REPORT 2025

Financial Statements
for the period ended December 31, 2025

**BLACKSWAN®
FOUNDATION**

Swiss foundation for research on orphan diseases
Fondazione svizzera per la ricerca sulle malattie orfane
Fondation suisse pour la recherche sur les maladies orphelines
Schweizerische Stiftung für die Forschung seltener Krankheiten



Fiduciaria Ortell SA
Via Gheina 2, 6900 Lugano (CH)
Tel. +41 91 922 11 10
<http://fiduciariaortelli.ch>

**Blackswan Fondazione -
Per La Ricerca Sulle Malattie Orfane**
Via Cantonale 26
6948 Porza

Lugano, il 19 Giugno 2026

Rapporto di revisione dell'ufficio di revisione al Consiglio di Fondazione della
Blackswan Fondazione - Per La Ricerca Sulle Malattie Orfane, Porza

In qualità di Ufficio di revisione abbiamo verificato la contabilità ed il conto annuale (bilancio, conto d'esercizio e allegato) della Blackswan Fondazione - Per La Ricerca Sulle Malattie Orfane, Porza per l'esercizio chiuso al 31 dicembre 2025.

Il Consiglio di fondazione è responsabile dell'allestimento del conto annuale, mentre il nostro compito consiste nella sua verifica e nell'espressione di un giudizio in merito. Confermiamo di adempiere i requisiti relativi all'abilitazione professionale e all'indipendenza.

La nostra revisione è stata effettuata conformemente allo standard svizzero sulla revisione limitata, il quale richiede che la stessa venga pianificata ed effettuata in maniera tale che anomalie significative nel conto annuale possano essere identificate con un grado di sicurezza accettabile.

Una revisione limitata consiste essenzialmente nell'effettuare interrogazioni e procedure analitiche, come pure, a seconda delle circostanze, adeguate verifiche di dettaglio della documentazione disponibile presso l'entità sottoposta a revisione. Per contro, la verifica dei processi aziendali e del sistema di controllo interno, come pure interrogazioni e altre procedure miranti all'identificazione di atti illeciti o altre disposizioni legali, sono escluse da questa revisione.

Sulla base della nostra revisione non abbiamo rilevato fatti che ci possano fare ritenere che il conto annuale non sia conforme alle disposizioni legali e dell'atto di fondazione.

Fiduciaria Ortelli SA



Lorenzo Ortelli

Perito revisore abilitato

Allegato:

Conto annuale (bilancio, conto d'esercizio e allegato)

ATTIVI

	31.12.2025		31.12.2024	
	CHF		CHF	
Attivo circolante				
Liquidità	153'398.31	100%	75'987.61	100%
Banca Raiffeisen - CHF	77'952.08		27'585.88	
Banca Raiffeisen - EUR	75'446.23		48'434.38	
Banca Raiffeisen - USD	-		-32.65	
Totale attivo circolante	153'398.31	100%	75'987.61	100%
Attivo fisso				
Partecipazioni	-		-	
Immobilizzazioni materiali mobiliari	118.12	0%	157.50	0%
Mobilio e installazioni	118.12		157.50	
Totale attivo fisso	118.12	0%	157.50	0%
TOTALE ATTIVI	153'516.43	100%	76'145.11	100%

PASSIVI

Capitale di terzi a breve termine

Debiti per forniture e prestazioni	-		-	0%
Debiti per forniture e prestazioni (creditori)	-		-	
Ratei e risconti passivi	12'972.00		8'648.00	11%
Costi da pagare	12'972.00		8'648.00	
Totale capitale di terzi a breve termine	12'972.00		8'648.00	11%

Capitale proprio

Capitale sociale	59'603.41		59'603.41	78%
Capitale della Fondazione	59'603.41		59'603.41	
Riserve e risultati	80'941.02		7'893.70	10%
Risultati riportati	7'893.70		-55'945.16	
Risultato annuale	73'047.32		63'838.86	
Totale capitale proprio	140'544.43		67'497.11	89%
TOTALE PASSIVI	153'516.43		76'145.11	100%

	31.12.2025		31.12.2024	
	CHF		CHF	
RICAVI				
Ricavi	214'823.74	100%	138'184.24	100%
Ricavi da donazioni	184'635.81		88'950.24	
Ricavi da congressi	30'187.93		49'234.00	
TOTALE RICAVI	214'823.74	100%	138'184.24	100%
COSTI				
Spese amministrative	140'718.92	66%	71'674.81	52%
Sostegno a progetti e alla ricerca	54'950.24		56'000.00	
Costi congressi	76'334.83		1'577.77	
Tasse	460.00		120.00	
Spese amministrazione, legali, consulenze diverse	4'324.00		8'648.00	
Spese d'informatica	3'474.06		3'874.40	
Spese trasferta e rappresentanza	807.80		1'100.00	
Spese diverse (membership)	328.61		302.14	
Ammortamenti e rettifiche di valore dell'attivo fisso	39.38		52.50	
Spese finanziarie	1'057.50	0%	2'670.57	2%
Spese banca e diritti di custodia	453.22		397.43	
Differenze di cambio	604.02		2'272.81	
Ricavi da averi bancari	0.26		0.33	
Risultato estraneo, straordinario o relativo ad altri periodi	-	0%	-	0%
Costi straordinari o relativi ad altri periodi contabili	-		-	
Ricavi straordinari o relativi ad altri periodi contabili	-		-	
TOTALE COSTI	141'776.42	66%	74'345.38	54%
RISULTATO D'ESERCIZIO	73'047.32	34%	63'838.86	46%

31.12.2025

31.12.2024
CHF

INFORMAZIONI GENERALI

Scopo della fondazione

Sostenere la ricerca terapeutica per le malattie rare o orfane a causa della mancanza di sostegni finanziari sovente riscontrata dai laboratori di ricerca pubblica sulle malattie rare o orfane. Raccogliere fondi per sostenere la ricerca scientifica relativa al settore delle malattie rare o orfane. Finanziare la ricerca pre-clinica e clinica di malattie rare o orfane, con l'assegnazione di fondi alle richieste di laboratori di ricerca. Raccogliere fondi per sostenere la ricerca scientifica di una malattia rara specifica (ad esempio malattie metaboliche del fegato). Promuovere e finanziare l'applicazione terapeutica di nuovi protocolli scientifici al fine di trovare una cura alle malattie rare o orfane incurabili. Informare e educare il pubblico sulla problematica della malattie rare o orfane. Il Consiglio di fondazione avrà cura di evitare che per la gestione ordinaria dell'istituto venga consumato il patrimonio della Fondazione. Il Consiglio di fondazione è il solo competente a dirigere e sorvegliare direttamente o a mezzo di persone di sua fiducia la gestione dell'istituto nonché eventualmente a locarlo ad enti che ne assicurino il rispetto dello scopo della Fondazione stessa. La Fondazione persegue obiettivi di pubblica utilità ed opera pertanto senza scopo di lucro.

Data dell'atto di fondazione e dell'ultimo statuto

Data dell'atto di fondazione	11.02.2010
Data dell'ultimo statuto	25.01.2021

Informazioni su eventuali regolamenti

Non sussistono ulteriori regolamenti.

Indicazioni sul Consiglio di Amministrazione

	Firma	Firma
Menzel, Olivier, presidente, da Porza, in Vuarrens	collettiva a due	collettiva a due
Berti, Stefano, Membro, da Lugano, in Bern	collettiva a due	collettiva a due
Najar, Skander, Membro, da Wassen, in Meyrin	collettiva a due	collettiva a due
Soudani-Kamal, Karima, Membro, da Croglio, in Féchy	collettiva a due	collettiva a due
Ciriminna, Chiara, Membro, cittadina italiana, in Lausanne	collettiva a due	collettiva a due

Il consiglio direttivo è composto da 5 membri nominati a vita.

Nome dell'ufficio di revisione

Fiduciaria Ortelli SA Lugano

I PRINCIPI CONTABILI

In generale

Secondo disposizioni legali svizzere (32. capitolo del CO).

INFORMAZIONI RELATIVE A POSIZIONI DI BILANCIO

	31.12.2025	31.12.2024
	CHF	CHF
Elargizioni	54'950.24	56'000.00
ITPR1 ANTAXIA Project - Professor Muntoni (c/o UCL UK)	54'950.24	-
Insel Gruppe AG - Institutional Hospital	-	56'000.00
Spese amministrative	4'324.00	8'648.00
Fiduciaria Ortelli SA, Lugano (CH) - 2023 & 2024	4'324.00	8'648.00
Altre informazioni prescritte dalla legge		
Nessuna		

NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2025

1. ORGANIZATION

The BLACKSWAN Foundation (BSF) is a Swiss Foundation, established as a not-for-profit legal entity registered in Porza under statutes dated 15 April 2010 and in accordance with article 80 et seq. of the Swiss Civil Code. It is managed by a board of trustees. BSF contributes to the development of research on rare and orphan diseases worldwide. The Foundation supports research on all types of rare and/or orphan diseases, which makes its vision unique and helps find new solutions that can assist a wide 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 to at CHF 50,000, as stipulated in the original statutes of the BLACKSWAN Foundation.

2. GOVERNANCE

The Foundation Board is the Foundation's supreme body. It makes all decisions necessary or effective to achieve 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 a voluntary basis and may not claim any financial compensation other than expenses incurred, such as travel and accommodation. For activities beyond 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 for the benefit of the Foundation.

3. RECOGNITION OF DONATIONS

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

BLACKSWAN FOUNDATION AFFILIATIONS & PARTNERS

AFFILIATIONS

- **ProRaris** - Swiss rare disease alliance - www.proraris.ch
- **EURORDIS** - European alliance of patient organizations - www.eurordis.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

PARTNERS

- **IRDiRC** - International Rare Diseases Research Consortium — www.irdirc.org
- **ERDERA** - European Rare Diseases Research Alliance — www.erdera.org

PRORARIS



Alliance Maladies Rares – Suisse
Allianz Seltener Krankheiten – Schweiz
Alleanza Malattie Rare – Svizzera



RARE
DISEASES
INTERNATIONAL

MEMBERS OF THE FOUNDATION

BOARD OF DIRECTORS

CHAIRMAN AND FOUNDER

Dr OLIVIER MENZEL, PhD, MBA;
Vuarrens, Switzerland

MEMBERS

STEFANO BERTI

Swiss Agency for Development and Coopertion

CHIARA CIRIMINNA SWAN

Swiss Federal Institute of Technology (EPFL)

SKANDER NAJAR

NASK (Network for Advanced Strategy and
Knowledge)

KARIMA SOUDANI

HealthCare Consultant

ADVISORY BOARD

DEMIAN CONRAD, Branding & Communication;
Lausanne

SCIENTIFIC COMMITTEE

PRESIDENT

Prof. BARBARA WILDHABER MD, PD;
Children's Hospital, Geneva, Switzerland

MEMBERS

Prof. STYLIANOS E. ANTONARAKIS MD, PhD;
Head of the Dept. of Medical Genetics
and Development, Geneva, Switzerland

Prof. JACQUES S. BECKMANN, PhD;

Professor emeritus at the University of Lausanne,
Lausanne, Switzerland

Dr. JACQUES BIRRAUX MD;

Children's Hospital, Geneva, Switzerland

Prof. BRUNO DALLAPICCOLA MD;

Scientific Director of Pediatric Hospital
Bambino Gesù, Rome, Italy

Dr. CELIA DELOZIER-BLANCHET PhD;

Director of Clinical Services,
University of California, USA

Dr. MARISA JACONI PhD, MER;

University of Geneva, Switzerland

Prof. STANISLAS LYONNET MD, PhD;

Professor of Genetics, University of Paris,
Hospital Necker, France

Prof. MARTIN MEULI MD;

Head of Department of Pediatric Surgery
University Hospital of Zurich, Switzerland

Dr. MICHAEL NICOLAS PhD;

University of Lausanne, Switzerland

Prof. ALEXANDRE REYMOND PhD;

University of Lausanne, Switzerland

Dr. PATRICK SALMON Pharm., PhD;

University of Geneva, Switzerland

Prof. HAMISH S. SCOTT PhD;

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

SWIFT: RAIFCH22XXX

CONTACT

BLACKSWAN Foundation
Chemin de la Riaz 11
1418 Vuarrens - Switzerland

contact@blackswanfoundation.ch

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

BLUESKY

<https://bsky.app/profile/rarevolution.bsky.social>

LINKEDIN

www.linkedin.com/company/blackswan-foundation
www.linkedin.com/grp/home?gid=3830895

INSTAGRAM

[instagram.com/blackswan_foundation/](https://www.instagram.com/blackswan_foundation/)

FLICKR

<https://www.flickr.com/photos/blackswanfoundation/>

BLACKSWAN[®]
FOUNDATION

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