Rapport Annuel
Annual Report
2023 & 2024

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

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WE AMPLIFY COLLECTIVE ACTION FOR RESEARCH ON RARE DISEASES

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASES
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MESSAGE DU PRÉSIDENT

Les années 2023 et 2024 sont fortement marquées par une instabilité géopolitique. Au moment où nous commencions à voir une lueur d'espoir postpandémique concernant les levées de fonds, l'espace financier philanthropique s'est complètement mis en pause, par crainte d'une situation économique mondiale incertaine.

Et, malheureusement, cela confirme mes craintes exprimées ces années précédentes quant à la possibilité de financer des projets de recherche dans les années à venir. Une première conséquence a été, avec regret, de mettre en pause notre projet d'institut, le RE(ACT) Discovery Institute, qui soutient la recherche scientifique innovante dans le domaine des maladies rares et répond aux besoins médicaux insatisfaits.

Cependant, les années 2023 et 2024 sont également marquées par un soutien direct à certains projets de recherche, ainsi que par la septième édition, en 2023, du congrès RE(ACT), qui a connu un franc succès et qui maintient sa position unique de plateforme internationale de rencontres pour les acteurs du domaine de la recherche.

Encore une fois, je remercie du fond du cœur mes collègues du conseil de la Fondation pour leur engagement et pour le développement de notre Fondation tout au long de cette année. Je suis convaincu que 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

IThe years 2023 and 2024 are marked by significant geopolitical instability. Just as we were beginning to see a glimmer of post-pandemic fundraising hope, the philanthropic sector came to a complete standstill amid fears of an uncertain global economic situation.

Unfortunately, this confirms my concerns expressed in previous years about funding research projects in the years ahead. One immediate consequence was to put our institute project, the RE(ACT) Discovery Institute, on hold. This institute supports innovative scientific research on rare diseases and addresses unmet medical needs in this field.

However, 2023 and 2024 will also see direct support for certain research projects, as well as the seventh edition of the RE(ACT) congress in 2023, which has been a great success and continues to maintain its unique position as an international meeting platform for stakeholders in research.

Once again, I would like to express my heartfelt thanks to my colleagues on the Foundation's board for their commitment and for the development of our Foundation throughout this year. I am convinced that 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 également que les maladies rares réduisent souvent l'espérance de vie de ceux qui en souffrent.

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). 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 par le système de santé, 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 au moins 80 % ont une origine génétique et 75% touchent des enfants. 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 souvent mortelles ou incapacitantes chez eux. Ce qui fait que le corps médical peine souvent à établir un diagnostic en raison du faible nombre de personnes touchées. Outre la difficulté à se faire reconnaître et une espérance de vie réduite, les malades souffrent de handicaps qui entraînent la discrimination et l'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 considered rare in Europe and Switzerland when it affects fewer than 1 in 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.

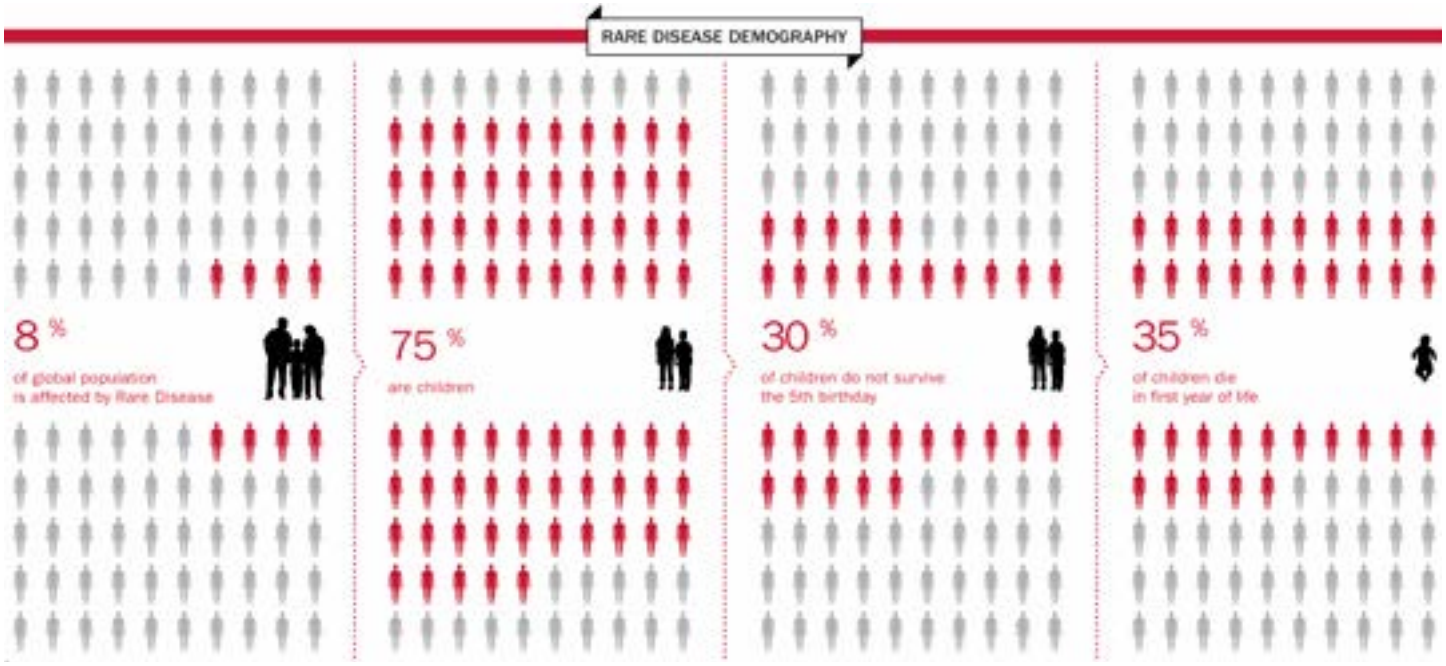
There is no internationally accepted definition of rare diseases. For example, in the United States, a condition is rare when it affects 1 in 1,500 people (or fewer than 200,000 citizens). Furthermore, a rare disease is considered orphan if no treatment has been developed. Practitioners do not know the condition, research is not ongoing, and it is extremely difficult to receive a diagnosis due to a 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 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 which are genetic in origin and 75% occur in children. 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 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 MAJEURES

> 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 à la recherche en raison du manque d'expertise des commissions internationales d'évaluation des projets et du nombre restreint de publications scientifiques des chercheurs qui sollicitent 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 grande échelle.
On l'a vu dans le cas de la leucémie, maladie qui est 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 de leucémie rare chez les enfants, réfractaire aux médicaments alors 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 sur des compétences pluridisciplinaires et des 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.

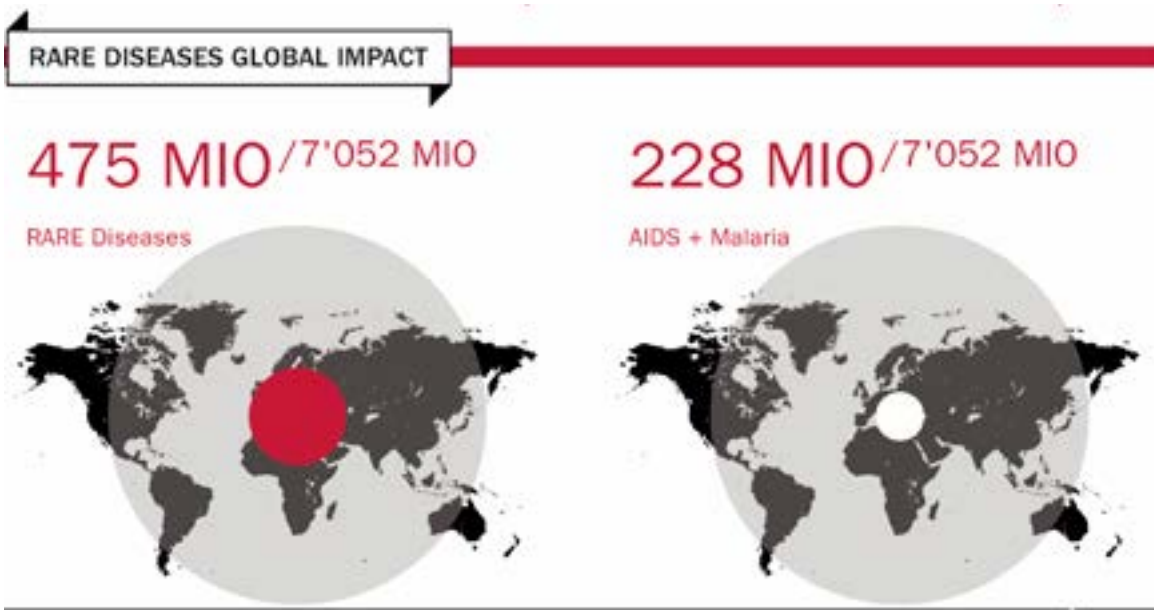
RESEARCH ON RARE DISEASES FACES SEVERAL MAJOR CHALLENGES

> 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, which affect a minimal number 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, a large pharmaceutical company developed a drug designed to cure a rare pediatric form of leukemia that was resistant to the drugs available at the time on the market. This drug was later shown to be effective against all types of leukemia.
In recent years, some start-ups and companies specializing in developing drugs for rare diseases have found their business models effective.
To meet the challenge of research, however, specialists must exchange best practices and use collaborative models to ensure as many patients as possible participate in research. There is a need to strengthen partnerships between academia and industry to develop 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 impliqués dans ce combat. Elle soutient la recherche sur tous les types de maladies rares ou orphelines, ce qui la rend unique au monde.

Outre son travail de collecte de fonds, elle organise tous les deux ans un congrès intitulé RE(ACT) – Rare Disease Research Congress, devenu une référence internationale. En sept éditions, plus de 1'800 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 pour la recherche et 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 the most common diseases.

The BLACKSWAN Foundation was established in Switzerland in 2010 to advance research on rare and orphan diseases worldwide. The Foundation supports research on all types of rare and orphan diseases, making its vision unique and enabling the discovery of new solutions that can assist a wide variety of projects.

In addition to its funding research mission, the Foundation organizes the RE(ACT) – Rare Disease Research Congress every two years, which has become an international reference point for rare disease experts. In the seventh edition, more than 1,800 scientists established approximately 50 collaborations.

Since 2015, BLACKSWAN Foundation has launched an international advocacy and awareness campaign called #RAREvolution to ensure that 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

2023 & 2024 ACTIVITIES SUPPORT FOR SCIENTIFIC RESEARCH

in english only

RE(ACT)

15-18 March 2023 – Berlin, Germany

We empowered a community that deserves to be heard. #RAREvolution

The seventh edition of the RE(ACT) - Rare Disease Research Congress and the fifth edition of the IRDiRC Conference were held jointly in person in Berlin (Germany) from 15-18 March 2023.

The event was organized by the BLACKSWAN Foundation in collaboration with the International Rare Diseases Research Consortium (IRDiRC) and the European Joint Programme on Rare Diseases (EJP RD). The congress was also supported by Rare Diseases International (RDI) and EURORDIS.

More than 150 attendees participated in the four-day congress, including scientists, physicians, patients, patient organizations, representatives from the pharmaceutical, biotech, and MedTech industries, start-ups, and other international stakeholders. The congress featured world-class speakers, panellists, and participants who shared their vision, experiences, and innovative scientific research on rare diseases.

The full list of speakers and panellists is available at http://www.react-congress.org/speakers/.

The congress presented the latest advances in knowledge, understanding, and innovation in rare disease research and offered an expanded view of health systems for rare diseases. Focused sessions addressed new tools and technologies for diagnosis, progress and challenges in advanced therapies for rare diseases, clinical research, regulatory science, and solutions to improve access.

The event provided an excellent opportunity for attendees to learn about cutting-edge research and network with other experts in the field of rare diseases.

2023 & 2024 ACTIVITIES SUPPORT FOR SCIENTIFIC RESEARCH

2024: SUPPORT TO DR. TIZIANA CREMONA AT THE INSTITUTION HOSPITAL BERN, SWITZERLAND, DEPARTMENT OF BIOMEDICAL RESEARCH

Project title:
Correction of the ZZ mutation in Alpha-1 Antitrypsin-deficient hepatocytes is achieved through the utilization of engineered extracellular vesicles.

Amount:
CHF 56'000

Summary:
In the current proposal, we aim to investigate Base editors (BEs)- mediated targeted, cell-specific or corrections in hepatocytes derived from iPSC lines from patients with AATD carrying the ZZ mutation. We aim to use engineered EVs as a delivery system.

Report (2025):
Alpha-1 antitrypsin (AAT) deficiency is a genetic disorder that mainly affects the liver and lungs. Our research explores a new way to treat this condition by using Extracellular Vesicles (EVs) from liver cells to deliver Base Editors (BEs) directly to the liver.

Key Findings:
- EVs produced by liver cells can efficiently target and enter liver cells.
- We tested this in the lab using liver cells (Hepa 1-6) and found that EVs were only absorbed by liver cells, not by other cell types such as lung epithelial cells (A549).
- We successfully loaded a green fluorescent protein (GFP) into EVs to track them. When delivered to liver cells, GFP was visible after 20 hours, proving effective delivery.
- To understand how EVs move inside the body, we labelled them with a dye and injected them into mice. Imaging showed that within 48 hours, EVs mainly accumulated in the liver.

Base Editing for Gene Correction:
- We tested whether BEs could correct the mutation causing AAT deficiency.
- We used pallid mice, which have a genetic defect in AAT and develop emphysema at 8 months of age. Healthy (C57BL6) mice were used as controls.
- We designed a guide RNA (gRNA) to recognize and correct the mutation in pallid mice.
- After testing various BEs and gRNAs, we identified the optimal sequence for gene correction.
- Testing on primary pallid liver cells showed a 13% correction of the mutation after 72 hours.
- Short-term tests in pallid mice (2 weeks after delivery) showed a 6% correction of the mutation.

Conclusion:
This research indicates that EVs can selectively target liver cells, presenting a promising strategy for treating AAT deficiency. BEs successfully correct the mutation in vitro and in vivo, though with varying efficiencies; additional studies are required. If the correction remains stable over time—particularly in vivo—and enables liver repopulation of corrected cells, it could pave the way for novel therapies for patients with this genetic disorder.

2023 & 2024 ACTIVITIES INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

2024: FUNDRAISING “ONE DONATION = SUPPORT FOR RESEARCH INTO RARE DISEASES “ ON QOQA PLATFORM: CHF 80,000 IN 24 HOURS

2023 & 2024 ACTIVITIES INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

CONCERT “LES DÉCOUVERTES MUSICALES” AU TEMPLE DU LOCLE

Le Temple du Locle a accueilli des ensembles de musique de chambre des régions neuchâteloise et lausannoise. Les musiciens sont actuellement élèves des conservatoires de Lausanne et du canton de Neuchâtel et ont proposé un programme d’envergure, alliant création contemporaine et grand répertoire. Ce concert a pris forme grâce au magnifique travail de professeurs tels que Hans Egidi, François Gottraux et Estefania Casanovas, qui ont préparé les ensembles. Les participants ont eu l’honneur d’assister à la création du quatuor de Noam Marlève, jeune étudiant du Conservatoire de Lausanne, violoniste et compositeur. Dans un programme riche et coloré, nous avons voyagé dans le temps avec, entre autres, des pièces baroques, classiques et romantiques, ainsi que dans l’espace, avec des compositeurs de diverses origines.
Une collecte a été organisée en faveur de notre Fondation. Nous tenons à remercier du fond du cœur tous les participants, les artistes et Mme Fanny Peguiron.

FINANCIAL REPORT 2023

Auditors' Report

on the financial statements
for the period ended December 31, 2023

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 ORTELLI

Fiduciaria Ortelli SA

FIDUCIARIA
ORTELLI

Blackswan Fondazione -
For research of orphan diseases
Via Cantonale 26
6948 Porza

Lugano, 17th April 2025

Report of the statutory auditor on the financial statements of

Blackswan Foundation - For research of orphan diseases, Porza

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As statutory auditor, we have audited the accompanying financial statements of Blackswan Foundation, which comprise the balance sheet, income statement and notes for the year ended 31 December 2023.

These financial statements are the responsibility of the Foundation Board. Our responsibility is to perform a limited statutory examination on these financial statements. We confirm that we meet the licensing and independence requirements as stipulated by Swiss law.

We conducted our examination in accordance with the Swiss Standard on the Limited Statutory Examination. This standard requires that we plan and perform a limited statutory examination to identify material misstatements in the financial statements. A limited statutory examination consists primarily of inquiries of personnel and analytical procedures as well as detailed tests of documents of the unit as considered necessary in the circumstances. However, the testing of operational processes and the internal control system, as well as inquiries and further testing procedures to detect fraud or other legal violations, are not within the scope of this examination.

Based on our limited statutory examination, nothing has come to our attention that causes us to believe that the financial statements do not comply with Swiss law.

We note that the foundation board did not submit to the supervisory authority, within six months of the end of the financial year, the audit report, the minutes of the approval of the financial statements, the duly signed accounts, and the activity report.

Fiduciaria Ortelli SA

Lorenzo Ortelli
Licensed audit expert
(Auditor in charge)

Attachment:
Financial Statements (Financial Statement, Income Statement e Notes to the Financial Statement)

BLACKSWAN®
FOUNDATION

Financial Statement

ASSETS	31.12.2023		31.12.2022	
	CHF	%	CHF	%
Current assets				
Cash and cash equivalents	**7'756.25**	97%	**41'477.41**	67%
Bank account	7'756.25		41'477.41	
Total current assets	**7'756.25**	97%	**41'477.41**	67%
Fixed Assets				
Investments	**-**	0%	**20'000.00**	32%
Investments	-		20'000.00	
Tangible assets	**210.00**	3%	**280.00**	0%
Office furniture and equipment	210.00		280.00	
Total Fixed Assets	**210.00**	3%	**20'280.00**	33%
TOTAL ASSETS	**7'966.25**	100%	**61'757.41**	100%

LIABILITIES				
Third party capital				
Suppliers or creditors	**2'154.00**	27%	**-**	0%
Suppliers or creditors	2'154.00		-	
Accruals and deferred income	**2'154.00**	27%	**2'154.00**	3%
Accrued expenses	2'154.00		2'154.00	
Short-term third party capital	**4'308.00**	54%	**2'154.00**	3%
Foundation equity	**59'603.41**	743%	**107'046.89**	173%
Foundation equity	59'603.41		107'046.89	
Reserves/Profit or Loss for the year	**-55'945.16**	-702%	**-47'443.48**	-77%
Profit / Loss for the year	-55'945.16		-47'443.48	
Total equity	**3'658.25**	46%	**59'603.41**	97%
TOTAL LIABILITIES	**7'966.25**	100%	**61'757.41**	100%

BLACKSWAN®
FOUNDATION
Profit & Loss Statement

PROFIT & LOSS STATEMENT	2023	2022
	CHF	CHF
Revenues from supplies and services	**107'284.61**	**33'371.08**
Revenues from donations and offers	2'582.62	33'371.08
Ricavi da congressi	104'701.99	-
Costs for material, goods, services and energy	**493.85**	**70'500.00**
Support for projects and research	493.85	70'500.00
Gross operating result after deducting costs for materials and goods	**106'790.76**	**-37'128.92**
Personnel expenses	**301.55**	**705.00**
Travel and entertainment expenses effective	301.55	705.00
Other operating expenses, dep., value adj. and fin. results	**135'408.33**	**8'667.55**
Conventions expenses	129'701.80	-
Taxes	200.00	200.00
General and Administrative Expenses	4'308.00	5'385.00
IT costs	1'198.53	3'082.55
Operating result before dep. and value adj., fin. results and taxes (EBITDA)	**-28'919.12**	**-46'501.47**
Depreciation and value adjustments of fixed assets	**70.00**	**100.00**
Depreciation and value adjustments of fixed assets	70.00	100.00
Operating result before financial results and taxes (EBIT)	**-28'989.12**	**-46'601.47**
Financial costs and revenue	**685.03**	**1'380.51**
Bank costs	293.53	274.24
Foreign Exchange differences	433.55	1'106.27
Financial revenue	-42.05	-
Operating result before taxes (EBT)	**-29'674.15**	**-47'981.98**
Results extraordinary or for other accounting periods	**26'271.01**	**-538.50**
Extraordinary or costs relating to other accounting periods	26'309.96	-
Extraordinary or revenue relating to other accounting periods	-38.95	-538.50
Profit or loss before taxes	**-55'945.16**	**-47'443.48**
Direct taxes	**-**	**-**
Direct taxes	-	-
Annual profit or loss	**-55'945.16**	**-47'443.48**

BLACKSWAN®
FOUNDATION

Notes to the financial statement

General information

The foundation BLACKSWAN FOUNDATION was registered on 15.04.2010. It's activities comprise a therapeutic research for rare or orphan diseas due to the lack of financial support often encountered by public research laboratories on rare of orphan diseases.

Accounting principles

The annual financial statements have been prepared in compliance with the principles established by the Swiss Code of Obligation, valid from 01.01.2015 (Article 957 - 963b CO).

Name, legal form and location

BLACKSWAN FOUNDATION - FOR RESEARCH ON ORPHAN DISEASES
Via Cantonale 26
CH - 6948 Porza

Average annual full time job positions

No employees

Participation in other companies

RE(ACT) DISCOVERY INSTITUTE SARL
Route de la Corniche 5
CH - 1066 Epalinges

Important events following the closing date

On May 31, 2024, the Court of Lausanne disposed the dissolution of the company Commercial Register RE(ACT) DISCOVERY INSTITUTE SARL. On November 1, 2024, it was removed from the Commercial Register in accordance with Article 159a, paragraph 2, letter b of the Swiss Code of Obligations (ORC).

Other informations prescribed by law

Leasing

FINANCIAL REPORT 2024

Rapporto dell'Ufficio di revisione

sul conto annuale al 31 dicembre 2024 della

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 ORTELLI

Fiduciaria Ortelli SA

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

Lugano, il 23 Dicembre 2025

Rapporto di revisione dell'ufficio di revisione al Consiglio di Fondazione della

Blackswan Fondazione - Per La Ricerca Sulle Malattie Orfane, Porza

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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 2024.

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.

Rileviamo che il Consiglio di fondazione non ha presentato entro sei mesi dalla chiusura dell'esercizio contabile all'autorità di vigilanza il rapporto all'ufficio di revisione, il verbale di approvazione dei conti e i conti debitamente firmati e il rapporto di attività.

Fiduciaria Ortelli SA
Lorenzo Ortelli
Perito revisore abilitato

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

ATTIVI

	31.12.2024 CHF		31.12.2023 CHF	
Attivo circolante				
Liquidità	**75'987.61**	*100%*	**7'756.25**	*97%*
Banca Raiffeisen - CHF	27'585.88		1'925.31	
Banca Raiffeisen - EUR	48'434.38		5'785.03	
Banca Raiffeisen - USD	-32.65		45.91	
Totale attivo circolante	**75'987.61**	*100%*	**7'756.25**	*97%*
Attivo fisso				
Partecipazioni	-		-	
Immobilizzazioni materiali mobiliari	**157.50**	*0%*	**210.00**	*3%*
Mobilio e installazioni	157.50		210.00	
Totale attivo fisso	**157.50**	*0%*	**210.00**	*3%*
TOTALE ATTIVI	**76'145.11**	*100%*	**7'966.25**	*100%*

PASSIVI

Capitale di terzi a breve termine				
Debiti per forniture e prestazioni	**-**	*0%*	**2'154.00**	*27%*
Debiti per forniture e prestazioni (creditori)	-		2'154.00	
Ratei e risconti passivi	**8'648.00**	*11%*	**2'154.00**	*27%*
Costi da pagare	8'648.00		2'154.00	
Totale capitale di terzi a breve termine	**8'648.00**	*11%*	**4'308.00**	*54%*
Capitale proprio				
Capitale sociale	**59'603.41**	*78%*	**59'603.41**	*748%*
Capitale della Fondazione	59'603.41		59'603.41	
Riserve e risultati	**7'893.70**	*10%*	**-55'945.16**	*-702%*
Risultati riportati	-55'945.16			
Risultato annuale	63'838.86		-55'945.16	
Totale capitale proprio	**67'497.11**	*89%*	**3'658.25**	*46%*
TOTALE PASSIVI	**76'145.11**	*100%*	**7'966.25**	*100%*

	31.12.2024 CHF		31.12.2023 CHF	
RICAVI				
Ricavi	**138'184.24**	*100%*	**107'284.61**	*100%*
Ricavi da donazioni	88'950.24		2'582.62	
Ricavi da congressi	49'234.00		104'701.99	
TOTALE RICAVI	**138'184.24**	*100%*	**107'284.61**	*100%*
COSTI				
Spese amministrative	**71'674.81**	*52%*	**136'273.73**	*127%*
Sostegno a progetti e alla ricerca	56'000.00		493.85	
Costi congressi	1'577.77		129'701.80	
Tasse	120.00		200.00	
Spese amministrazione, legali, consulenze diverse	8'648.00		4'308.00	
Spese d'informatica	3'874.40		1'198.53	
Spese trasferta e rappresentanza	1'100.00		301.55	
Spese diverse (membership)	302.14		-	
Ammortamenti e rettifiche di valore dell'attivo fisso	52.50		70.00	
Spese finanziarie	**2'670.57**	*2%*	**685.03**	*1%*
Spese banca e diritti di custodia	397.43		293.53	
Differenze di cambio	2'272.81		433.55	
Ricavi da averi bancari	0.33		-42.05	
Risultato estraneo, straordinario o relativo ad altri periodi	**-**	*0%*	**26'271.01**	*24%*
Costi straordinari o relativi ad altri periodi contabili	-		26'309.96	
Ricavi straordinari o relativi ad altri periodi contabili	-		-38.95	
TOTALE COSTI	**74'345.38**	*54%*	**163'229.77**	*152%*
RISULTATO D'ESERCIZIO	**63'838.86**	*46%*	**-55'945.16**	*-52%*

	31.12.2024 CHF	31.12.2023 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

	31.12.2024 CHF	31.12.2023 CHF
Elargizioni	**56'000.00**	**493.85**
Insel Gruppe AG - Institutional Hospital	56'000.00	
SSADH-Deficit e.V. - Poster prize CureRare		493.85
Spese amministrative	**8'648.00**	**4'308.00**
Fiduciaria Ortelli SA, Lugano (CH) - 2023 & 2024	8'648.00	-
Newgest SA, Lugano (CH) - 2022	-	4'308.00

Altre informazioni prescritte dalla legge
Nessuna

Blackswan Fondazione - Per la ricerca sulle malattie orfane, Porza
Proposta d'impiego dell'utile di bilancio

	31.12.2024 CHF	31.12.2023 CHF
Riporto di inizio periodo	**-55'945.16**	-
Risultato d'esercizio	63'838.86	-55'945.16
Totale a disposizione	**7'893.70**	**-55'945.16**
Riporto a nuovo	**7'893.70**	**-55'945.16**

NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2023 & 2024

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 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 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 achieving 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

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 AFFILIATIONS & PARTNERS

- **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

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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

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

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