Rapport Annuel

Annual Report

2021

BLACKSWAN®
FOUNDATION

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASE S
SCHWEIZERISCHE STIFTUNG FÜR DIE FORSCHUNG SE LTENER KRANKHEITEN
FONDATION SUISSE POUR LA RECHERCHE SUR LES MALADIES ORPHELINE S
FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALA TTIE ORFANE

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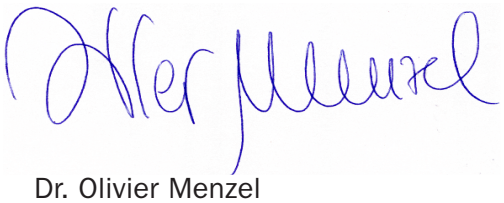
MESSAGE DU PRÉSIDENT

L'année 2021 est encore une année marquée par la pandémie qui paralyse toutes activités et qui ne nous permet pas d'organiser des événements ni des levées de fonds, ce qui personnellement me fait douter de la possibilité de financer des projets de recherche ces prochaines années.

Cependant, l'année 2021 est une année très importante pour la Fondation car nous avons créé le RE(ACT) Discovery Institute, le premier institut au monde, à but non lucratif et sous la forme juridique d'une société à risque limitée qui appartient 100% à la Fondation. Le RE(ACT) Discovery Institute soutient la recherche scientifique innovante dans le champ des maladies rares et répond aux besoins médicaux non satisfaits dans ce domaine.

Pour ma part, je souhaite que l'institut puisse se développer et faire avancer différents projets pour enfin amener des nouvelles solutions thérapeutiques aux personnes vivant avec une maladie orpheline. Ce fut un privilège de participer à la création de ce projet innovateur et je remercie du fond du cœur mes collègues au sein du conseil de Fondation pour leur travail et 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

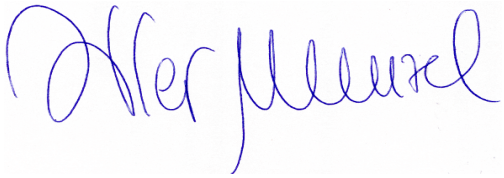
"Nous travaillons dur pour tirer le meilleur parti de chaque centime investi dans la recherche!"

MESSAGE FROM THE PRESIDENT

The year 2021 is still a year marked by the pandemic that paralyzes all activities and does not allow us to organize events or fundraising, which personally makes me doubt the possibility of funding research projects in the coming years.

However, 2021 is a very important year for the Foundation because we have created the RE(ACT) Discovery Institute, the world's first not-for-profit institute in the legal form of a limited-risk company that is 100% owned by the Foundation. The RE(ACT) Discovery Institute supports innovative scientific research in the field of rare diseases and addresses unmet medical needs in this area.

My wish is that the institute will be able to develop and advance different projects to finally bring new therapeutic solutions to people living with an orphan disease. It has been a privilege to participate in creating this innovative project, and I thank my colleagues on the Board from the bottom of my heart for their work and development of our Foundation throughout this year. I am sure 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 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 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 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;

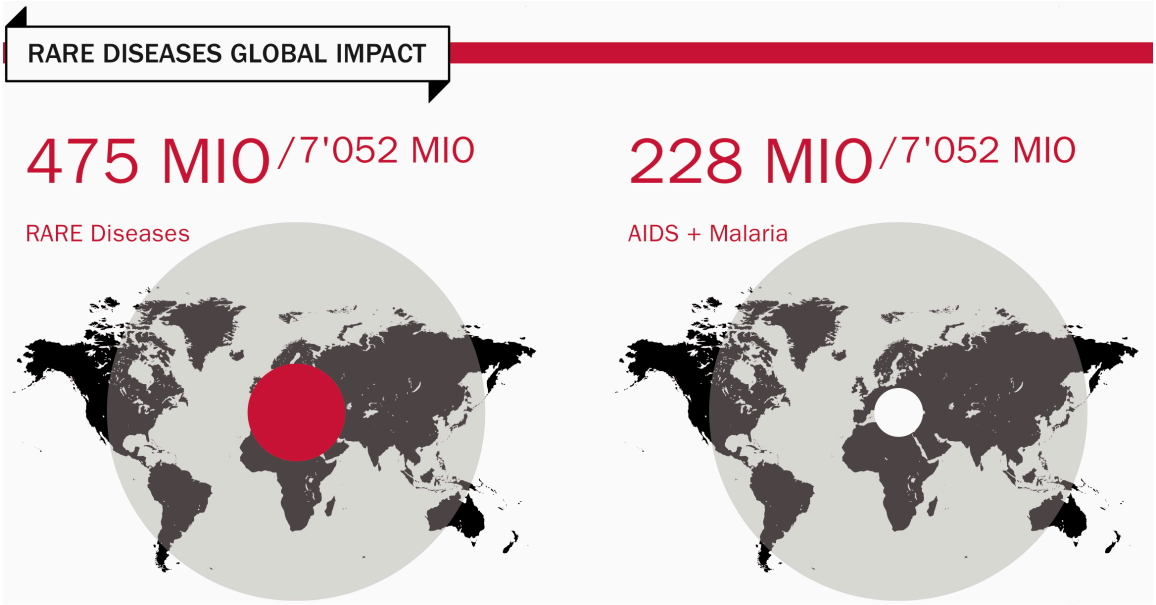
> Financial barriers: National public funding agencies are not proactive in supporting research because of the lack of expertise of international project assessment boards and of the limited number of scientific publications by researchers requesting funding.

> 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

2021 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

FONDATION DU RE(ACT) DICOVERY INSTITUTE

Le RE(ACT) Discovery Institute est un institut unique, à but non lucratif, qui soutient la recherche scientifique innovante dans le champ des maladies rares et répond aux besoins médicaux non satisfaits dans ce domaine. Émanation de la BLACKSWAN Foundation une fondation Suisse active au niveau mondial dans le soutien à la recherche sur les maladies rares et la création d'une communauté scientifique internationale , l'institut est installé au Biopôle, le campus des Sciences de la vie, à Epalinges près de Lausanne.

La mission du RE(ACT) Discovery Institute est de favoriser la découverte et le développement de nouvelles thérapies pour les maladies rares, affections qui touchent en moyenne 500'000 personnes en Suisse et quelques 500 millions au niveau mondial. L'institut vise à combler le fossé entre la recherche scientifique financée par des fonds publics et l'industrie pharmaceutique. Il veut permettre à la communauté scientifique suisse et mondiale travaillant sur un mécanisme spécifique, une protéine cible ou un processus impliqué dans l'apparition ou la progression d'une maladie, de faire passer leurs recherches du laboratoire au chevet du patient avec l'objectif d'en améliorer la qualité de vie.

L'institut a pour objectif de découvrir, collecter et internaliser des programmes de recherche en cours ou abandonnés et de poursuivre leur développement en agissant comme un "pont" entre le projet d'un groupe de recherche au stade de la "découverte" et le développement clinique final. En s'inspirant d'organisations existantes et de centres de recherche et de développement de médicaments travaillant avec des universités et des industries principalement des start-ups , l'institut fournit les ressources et l'expertise nécessaires au développement de nouveaux médicaments jusqu'à leur commercialisation.

Le RE(ACT) Discovery Institute a donc pour objectif d'être un accélérateur de la recherche en matière de développement thérapeutique. Par-là il cherche à permettre aux laboratoires de recherche disposant de technologies modernes de pointe de découvrir et de développer des traitements potentiels et des outils de diagnostic pour les maladies rares. L'institut vise également la création de partenariats avec des universités et des instituts de technologie nationaux ou internationaux, des hôpitaux, des instituts de recherche, des fondations et des associations de patients.

Pendant la première séance du Conseil d'Administration, qui a eu lieu le 24 septembre, la présidente Prof. Nouria Hernandez, a souligné l'urgence de cette initiative : « C'est un magnifique projet qui répond à un besoin urgent, celui de tous les patients souffrant de maladies encore peu expliquées pour lesquelles il n'existe pas, ou que peu, de traitements ».

De son côté, le Dr. Olivier Menzel, fondateur et président de BLACKSWAN Foundation, a mis l'accent sur l'importance fondamentale de la recherche sur ces maladies : « La recherche sur les maladies rares est de la plus haute importance, non seulement parce que les personnes vivant avec une maladie rare ne sont pas rares du tout (on estime à un demi-milliard le nombre de personnes dans le monde), mais surtout parce que la recherche sur les maladies rares fait progresser les connaissances sur les maladies communes et apporte de nouvelles solutions thérapeutiques pour tous ».

2021 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

INCEPTION 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 Institute is located at the Biopôle, the Life Sciences campus, in Epalinges near Lausanne.

The mission of the RE(ACT) Discovery Institute is to foster the discovery and development of new therapies for rare diseases, which affect an average of 500,000 people in Switzerland and some 500 million worldwide. The Institute aims to bridge the gap between publicly funded scientific research and industry-supported applied R&D. It seeks to enable the Swiss and global scientific community working on a specific mechanism, target protein, or process involved in disease onset or progression to move their research from the bench to the bedside, with the declared goal of improving the quality of life of patients.

The Institute aims to discover, collect, and internalize ongoing or discontinued research programs and further develop them by acting as a "bridge" between a research group's "discovery" stage project and the final clinical development. It takes inspiration from existing organizations and drug research & development centers working with universities and industries – mainly start-ups – to provide the resources and expertise to develop new drugs/treatments to a point where they can be licensed to industry.

The RE(ACT) Discovery Institute accelerates research in therapeutic development, enabling academic laboratories with cutting-edge modern technologies to discover and develop potential treatments and diagnostic tools for rare diseases. To fulfill its goal of accelerating drug discovery and drug development for the treatment of rare diseases, the Institute creates partnerships with national or international universities and institutes of technology, hospitals, research institutes, foundations, and patient associations interested in translational research and development.

The President of the Board of Directors, Prof. Nouria Hernandez, highlighted the importance of the project: "This is a wonderful project that responds to an urgent need, that of all patients suffering from diseases that are still poorly understood and for which there are few or no treatments".

Dr. Olivier Menzel, Chairman and Founder of the BLACKSWAN Foundation, stressed that: "Research on rare diseases is of most importance, not only because people living with a rare disease are not rare at all, mainly because research on rare disease advances progress knowledge in common disease and brings new therapeutic solutions for everyone".

Finally, Dr Davide Städler, noted that: "Research in the field of rare diseases is a scientific and human challenge that relies on the networking of specialists, and the orchestration of a whole series of multidisciplinary activities. Our Institute's mission is to build bridges linking all the actors involved, with the aim of rapidly producing innovative and effective rare diseases therapeutics".

2021 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

THE RE(ACT) CONGRESS & IRDIRC CONFERENCE 2021 – INTERNATIONAL CONGRESS OF RESEARCH ON RARE AND ORPHAN DISEASES

The sixth edition of the RE(ACT) Congress and the fourth edition of the IRDiRC Conference were held online in a first-time joint event on 13-15 January 2021, organized by the BLACKSWAN Foundation in collaboration with IRDiRC, International Rare Diseases Research Consortium, and EJP RD, European Joint Programme on Rare Diseases. The congress also benefited from the support of Rare Diseases International (RDI) and EURORDIS.

The event attracted around 300 attendees, including scientists, physicians, patient organizations, pharmaceutical industry representatives and start-ups, patients, and other international stakeholders. During the three-day conference, world-class speakers, panelists, and participants shared their vision, experiences and presented their innovative and outstanding scientific research on rare diseases. The full list of speakers and panelists is available at http://www.react-congress.org/speakers/.

The conference presented the latest advancements in knowledge, understanding, and innovation in rare diseases 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, innovative approaches for clinical trials for ultra-rare diseases, and methodologies to measure the impact of rare diseases diagnosis and treatments.
Emphasis was given to the barriers to access to approved therapies and treatments for patients as drivers in drug development and clinical trials. A hands-on workshop on the IRDiRC Orphan Drug Development guidebook and a rare diseases foresight session from across different areas of the globe completed the program.

Each session was followed by a panel discussion involving the speakers and one or more patient representatives, providing deep insights as fundamental and indispensable actors along the whole diagnostic and therapeutic path.

2021 ACTIVITIES
INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

Due to the COVID-19 outbreak, we could not organize any event to increase awareness and collect funds.

FINANCIAL REPORT 2021

Balance to 31.12.2021

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	2'488.19		100.00
1021	EUR	Bank account Raiffeisen EUR	71'027.52		100.00
1022	USD	Bank account Raiffeisen USD	18'436.18		100.00
1024		Bank account EFG CHF -007		7'811.45	0.00
1024.01		Bank account EFG CHF -015		11'319.71	0.00
1025	EUR	Bank account EFG EUR -031		76'605.60	0.00
1026	USD	Bank account EFG USD -058		14'621.09	0.00
Total Cash and bank accounts			91'951.89	110'357.85	83.32 +
Accruals					
1300		Accruals and prepaid expenses	100.00	7'900.00	1.27 +
Total Accruals			100.00	7'900.00	1.27 +
Total Current assets			**92'051.89**	**118'257.85**	77.84 +
Fixed assets					
Financial fixed assets					
1480.01		Part. RE(ACT) DISC. INST. SARL 100%	20'000.00		100.00
Total Financial fixed assets			20'000.00		100.00
Tangible assets					
1510		Furniture and installation	380.00	510.00	74.51 +
1521		Information technology		1'910.00	0.00
Total Tangible assets			380.00	2'420.00	15.70 +
Total Fixed assets			**20'380.00**	**2'420.00**	842.15 +
Total Assets			**112'431.89**	**120'677.85**	93.17 +

FINANCIAL REPORT 2021

Balance to 31.12.2021

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	100.00	
Total Accounts payable		-3'231.00	100.00	
Short-term onorous debts				
2141	Credit card debt	-595.15	0.00	
Total Short-term onorous debts		-595.15	0.00	
Other short-term payables				
2230	Debts to employees	-1'148.45	0.00	
2270	Pension plan debts	-14.60	0.00	
2271	Old-age security debts	-1'025.30	0.00	
Total Other short-term payables		-2'188.35	0.00	
Accruals				
2300	Accrued expenses	-2'154.00	-3'500.00	61.54 +
Total Accruals		-2'154.00	-3'500.00	61.54 +
Total Short-term third party capital		**-5'385.00**	**-6'283.50**	85.70 +
Total Current liabilities		**-5'385.00**	**-6'283.50**	85.70 +
Foundation equity				
Reserves/Profit or Loss of financial year				
2970	Profit/Loss account	-114'394.35	-258'696.85	44.22 +
Total Reserves/Profit or Loss of financial year		-114'394.35	-258'696.85	44.22 +
Total Foundation equity		**-114'394.35**	**-258'696.85**	44.22 +
Total Liabilities		**-119'779.35**	**-264'980.35**	45.20 +
Loss		-7'347.46	-144'302.50	5.09 +
TOTAL DR/CR		**112'431.89**	**120'677.85**	

FINANCIAL REPORT
2021 PROFIT & LOSS

	Account No	Account Name	Balance CHF	Prev. FY CHF		
Profit & Loss statement						
	3000	Revenues from donations, offers	16'295.00	48'041.66	33.92	+
+	Net revenues from supplies and services		16'295.00	48'041.66	33.92	+
=	**Revenues from supplies and services**		**16'295.00**	**48'041.66**	33.92	+
	4000	Support for projects and research		-51'086.22	0.00	
+	Costs for material, goods, services and energy			-51'086.22	0.00	
=	**Gross operating result after deducting costs for materials and goods**		**16'295.00**	**-3'044.56**	535.22	-
	5000	Wages		-52'506.61	0.00	
+	Personnel expenses			-52'506.61	0.00	
=	**Gross operating result after deducting personnel expenses**		**16'295.00**	**-55'551.17**	29.33	-
	6361	Taxes	469.29		100.00	
	6500	Office supplies		49.65	0.00	
	6501	Print	1'887.65	1'572.33	120.05	+
	6530	Accounting costs	5'956.86	3'339.96	178.35	+
	6532	Legal consultancy		4'122.70	0.00	
	6559	Other administration costs	1'760.00		100.00	
	6584	IT costs	1'371.50	8'684.64	15.79	+
	6640	Travel expenses	1'605.80	1'240.88	129.41	+
	6673	Conventions expenses	3'103.76	41'137.08	7.54	+
-	Other operating expenses		16'154.86	60'147.24	26.86	+
=	**Operating result before depreciation and value adjustments, financial results and taxes (EBITDA)**		**140.14**	**-115'698.41**	0.12	-
	6821	Depreciation office furniture	130.00	160.00	81.25	+
	6822	Depreciation information technology	761.55	1'270.00	59.96	+
	6845	Depreciation on development		26'630.00	0.00	
-	Depreciation and value adjustments of fixed assets		891.55	28'060.00	3.18	+
=	**Operating result before financial results and taxes (EBIT)**		**-751.41**	**-143'758.41**	0.52	+
	6940	Bank charges	958.91	544.09	176.24	+
	6947	Exchange loss USD	1'282.62		100.00	
	6949	Exchange loss EUR	5'377.15		100.00	
-	Financial costs		7'618.68	544.09	1'400.26	+
=	**Operating result before taxes (EBT)**		**-8'370.09**	**-144'302.50**	5.80	+
	8709	Extraordinary costs to other acc.periods	331.70		100.00	
-	Extraordinary or unique costs for other accounts periods		331.70		100.00	
	8719	Extraordinary revenue to other acc.periods	1'354.33		100.00	
+	Extraordinary or unique revenues for other accounts periods		1'354.33		100.00	
=	**Profit or loss before taxes**		**-7'347.46**	**-144'302.50**	5.09	+

NOTES TO FINANCIAL STATEMENTS

NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2021

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 31.12.2021 (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 31.12.2021 (art. 959c CO)

13. **Subsequent events**
    On January 29, 2020, due to the coronavirus, the Emergency Committee of the World Health Organization (WHO) declared a health emergency of international proportions. Since the pandemic is still ongoing, it is not possible to estimate the impact on the 2022 results.
14. **Audit office, possible resignation**
    On 07.10.2021 at the Commercial Register, the audit office was changed.
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

MEMBERS OF THE FOUNDATION

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CHAIRMAN AND FOUNDER

Dr OLIVIER MENZEL, PhD, MBA;
Vuarrens, Switzerland

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Swiss Agency for Development and Coopertion
CHIARA CIRIMINNA SWAN
Swiss Federal Institute of Technology (EPFL)
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Children's Hospital, Geneva, Switzerland

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University of Adelaide, Australia
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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
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contact@blackswanfoundation.ch

www.blackswanfoundation.ch
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BLACKSWAN®
FOUNDATION

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASE S
SCHWEIZERISCHE STIFTUNG FÜR DIE FORSCHUNG SE LTENER KRANKHEITEN
FONDATION SUISSE POUR LA RECHERCHE SUR LES MALADIES ORPHELINE S
FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALA TTIE ORFANE