Rapport Annuel

Annual Report

2018

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

TABLE DES MATIÈRE
TABLE OF CONTENTS

WE AMPLIFY COLLECTIVE ACTION FOR RESEARCH ON RARE DISEASES

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

MESSAGE DU PRÉSIDENT

En 2018, la Fondation BLACKSWAN a mis en place une nouvelle stratégie.

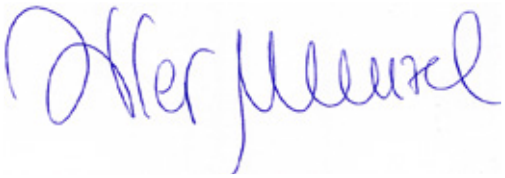
Nous avons lancé un projet pilote avec des parents d'enfants atteints d'une maladie rare afin de les aider à recueillir des fonds, à évaluer des projets scientifiques et à les examiner régulièrement. Cela a permis de financer 5 projets internationaux (plus un via la plateforme RE(ACT) Community de financement participatif), et au lieu de soutenir deux fois des projets trop similaires, nous avons opté plutôt pour créer une collaboration entre les groupes de recherche. Après deux ans, nous pourrons choisir le projet qui sera le plus pertinent sur le plan thérapeutique et concentrer nos efforts sur celui qui a une chance d'apporter un traitement à ces jeunes enfants.

Outre les collaborations internationales, une coopération structurée entre les associations de patients et les projets scientifiques est obligatoire pour maximiser le peu de ressources alloués à la recherche.

Nous avons tenu la quatrième édition du Congrès RE(ACT) 2018 à Bologne, Italie. Le congrès a été organisé par la Fondation BLACKSWAN et E-RARE, le réseau ERA-Net pour les programmes de recherche sur les maladies rares. L'événement a été un grand succès et a confirmé la nécessité des deux points développés précédemmant, soit l'amélioration des collaborations internationales et le besoin de créer un réseau solide entre les chercheurs et toutes les parties prenantes et donc de la légitimité de l'initiative RE(ACT) et du programme RAREvolution. Lors du Congrès RE(ACT), la Fondation BLACKSWAN a également lancé une pétition en ligne contenant neuf recommandations pour guider l'élaboration de politiques sur la recherche sur les maladies rares.

A la Fondation BLACKSWAN nous sommes convaincus que la collaboration de toutes les parties prenantes pour montrer l'importance des maladies rares dans le programme de santé permettra aux organisations internationales de reconnaître les maladies rares comme une priorité en matière de santé publique et de recherche et de sauver la vie de millions d'individus.

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 2018 the BLACKSWAN Foundation implemented a new strategy.

We started a pilot project with parents of children living with a rare disease to help them in fundraising, evaluate scientific projects, and reviewed them on a regular base. This resulted in financing five international projects (plus one via the crowdfunding platform RE(ACT) Community) and has prevented to support similar projects where we could ask scientists to collaborate.

After two years, we will be able to choose which project is going to be more therapeutically pertinent and concentrate our efforts on the one who has a chance to bring treatments to our young children.

Besides international collaborations, structured cooperation among patient organizations and scientific projects is mandatory to maximize the scarcity of resources for research.

We held the fourth edition of the RE(ACT) Congress 2018 in Bologna, Italy. The Congress was organized by the BLACKSWAN Foundation and E-RARE, the ERA-Net for Research Programs on RDs and was a great success in improving international collaborations and confirmed the ultimate need of creating a strong network amongst researchers and all stakeholders.

At the BLACKSWAN Foundation, we firmly believe that the collaboration of all stakeholders in showing the importance of rare diseases on the health agenda will bring international organizations to recognize rare diseases as a public health and research priority and save the lives of millions of individuals.

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 ?

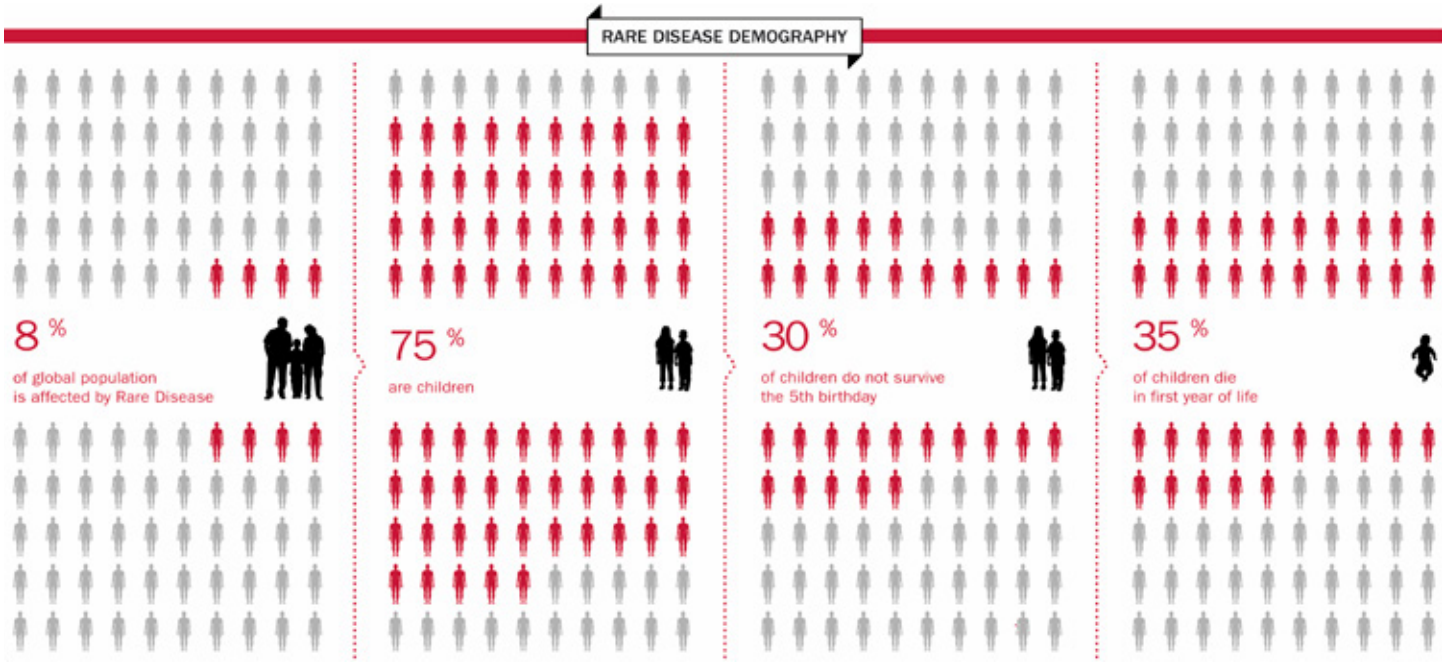
A disease or disorder is defined as rare in Europe and in Switzerland when it affects not more than 1 in every 2,000 persons. These conditions are generally chronic, progressive, debilitating and often life-threatening. In addition, these rare diseases present certain challenges for the development of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

There is no internationally accepted definition of rare diseases. For example, in the United States, a condition is rare when 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 per cent of them are genetic in origin. The remaining 20 per cent 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 and 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, there are associations that 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

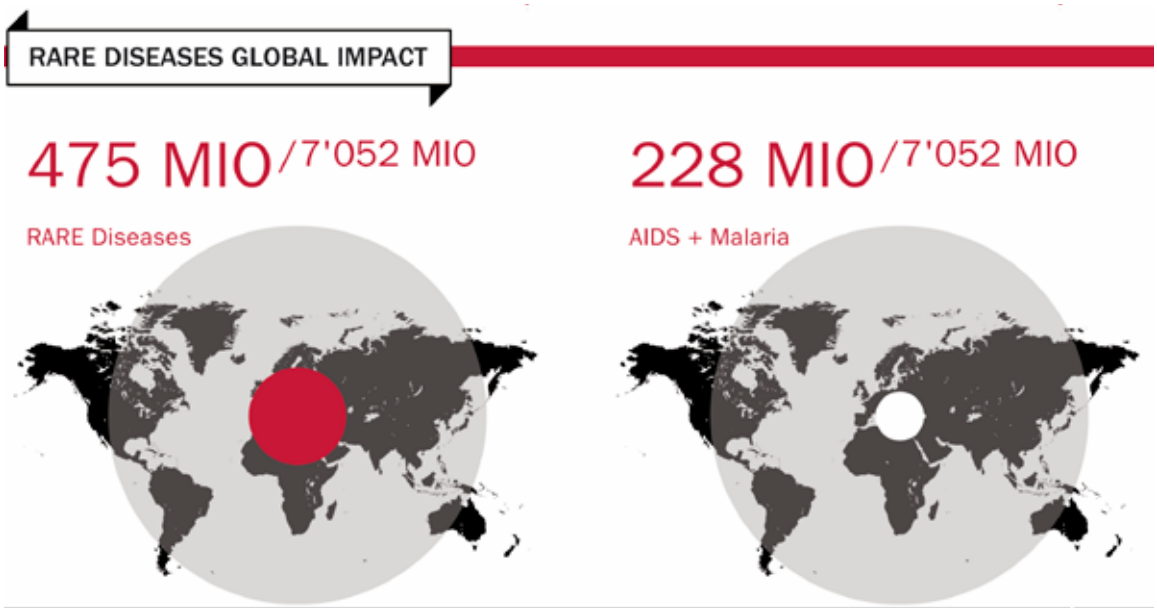
> Scientific obstacles: the small number of patients often does not allow to scientifically validate the results of the research work, which prevents the publication of articles that could mobilize the attention and interest of the research community;

> 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 affecting a very limited 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.

As has been seen 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 forms of leukemia.
In addition, 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.

In order to meet the challenge of research, however, it is necessary for specialists to exchange best practices and use collaborative models and that the largest number of patients participate in research. There is a need to strengthening the 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 trois éditions, plus de 1500 scientifiques ont pu mettre en place une cinquantaine de collaborations.

La RE(ACT) Community est quant à elle à la fois un outil de financement participatif (crowdfunding) et une plateforme d'échanges autour de cette problématique. 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 disease, which makes its vision unique and helps in finding new solutions that can assist a large variety of projects.

Besides its funding research mission, the Foundation organizes every two years the RE(ACT) Congress, which became an international reference point for rare disease experts. In three editions, more than 1,500 scientists were able to establish approximately fifty collaborations.

In 2014, the BLACKSWAN Foundation launched the RE(ACT) Community a crowdfunding and a knowledge sharing digital platform that connects researchers, patients and other rare disease stakeholders. Since 2015, BLACKSWAN Foundation has also started an international advocacy and awareness campaign called #RAREvolution to ensure rare diseases are recognized as an international 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

2018 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

in english only

FOXG1 Research is a special team created within the BLACKSWAN Foundation that supports research on FOXG1 syndrome.

1. **Correcting FOXG1 loss-of-function in post-natal animals. Identification of the etiology of FOXG1 syndrome and the targets for drug discovery.**

PI: Dr Soo-Kyung Lee – Oregon Health and Sciences University (Portland, USA).

Budget: USD 150'887

2. **FOXG1 as target for Autism. Gene targets of FOXG1 in human brain progenitors.**

PI: Dr Flora Vaccarino – Yale University (New Haven, USA)

Budget: USD 130,641

3. **RNA Gene Therapies for FOXG1 missense mutations. Developing an integrated platform for scalable, etiopathogenic-clinical profiling of subtle FOXG1 mutations and experimental, RNA-drive rescue of their histopathogenic effects**

PI: Dr Roberta Cilio – UCSF (USA) and Dr Antonello Mallamaci at SISSA (Trieste, Italy)

Budget: USD 125'000

4. **RNA gene therapy to correct FOXG1 symptoms in iPS cells. Assessing the therapeutic potential of small activating RNAs in a patient-derived cellular model of FOXG1 syndrome**

PI: Dr Angus Clarke – Cardiff University (Cardiff, UK)

Budget: USD 85,665

5. **Establishing and characterizing eight mouse model lines enabling researchers and biotechnology companies to trial therapies for FOXG1 Syndrome (FS)**

PI: Dr. Jae Lee, Oregon Health And Sciences University (OHSU) (Portland, USA).

Budget: USD 175'000

FOXG1 RESEARCH | BLACKSWAN® FOUNDATION

2018 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

THE RE(ACT) CONGRESS 2018 – INTERNATIONAL CONGRESS OF RESEARCH ON RARE AND ORPHAN DISEASES
MARCH 7-10, 2018 - BOLOGNA, ITALY

Collaboration is the key towards success in rare diseases research #RAREvolution

The fourth edition of the RE(ACT) Congress - International Congress of Research on Rare and Orphan Diseases, organized by the BLACKSWAN Foundation (http://www.blackswanfoundation.ch/en/) in collaboration with E-Rare (http://www.erare.eu/) has been held at the Rizzoli Institute – Istituto di ricerca Codivilla Putti in Bologna, Italy, from 7th to 10th March 2018.
The Congress supported by IRDiRC, Eurordis and Fondazione Telethon presented some of the most innovative and outstanding scientific research on rare diseases. The main topics discussed during the RE(ACT) Congress included NGS and undiagnosed rare diseases, pathophysiology, gene and cell therapies and neurological diseases.

Over the course of the meeting, a dedicated session on the opportunities in rare diseases research around the world provided to participants an overview of collaborative projects dedicated to the scientific community. Two workshops were also organized on the first day of the congress, one by the Undiagnosed Diseases Network International (UDNI) on undiagnosed diseases and the other one by the European Reference Network on Rare Bone Disorders (ERN-BOND) on European Reference Networks (ERNs).
The event involved more than 100 attendees: researchers, doctors, organizations, patients, sponsors and other international stakeholders and world-class speakers included Professor Silvio Garattini, Professor Harvey F. Lodish, Professor William Gahl, Professor Luigi Naldini, Professor Nicolas Lévy and many others. During the three days conference, they shared their studies and were the protagonists of a successful edition of the RE(ACT) Congress 2018. The full list of speakers is available at: http://www.react-congress.org/speakers.

2018 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

In his opening speech, Professor Silvio Garattini, founder and director of the Mario Negri Institute for Pharmacological Research highlighted three main reasons why rare diseases should be studied. He emphasized the right of patients to be cured independently from the type of their disease, the fact that rare diseases furnish information useful for common diseases, and the importance of rare diseases for the future since they pave the way to personalized medicine. He also opened a discussion on the importance of creating more incentives for ultra-rare diseases.

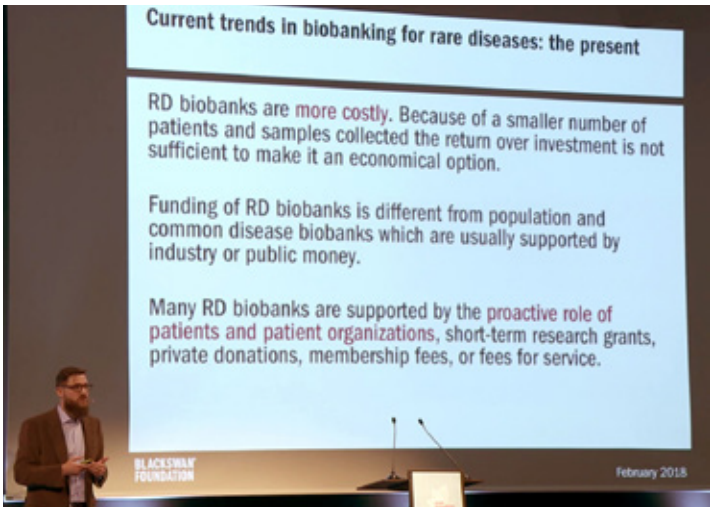
During the opening ceremony, Professor William Gahl, Senior investigator at the Intramural Research Program, National Institute of Health (NIH) underlined the importance of putting more effort on diagnosis within the international network.
The opening ceremony was closed by Harvey F. Lodish, Professor of Biology and Biological Engineering at the Massachusetts Institute of Technology (MIT) and Founding Member of the Whitehead and Broad Institute for Biomedical Research. Professor Lodish, who is the lead author of the textbook Molecular Cell Biology and the founder and Board member of several biopharmaceutical companies, provided a speech on Academic Entrepreneurs, New Technologies and Building Companies to Treat Rare Diseases. During his talk he emphasized the need for intense collaboration of different stakeholders to develop a cure for rare diseases. One of the take home messages of his presentation was on the importance of “geography” to push research forward and deliver new treatments, the importance of creating an ecosystem like the one the MIT and the Whitehead and Broad Institute for Biomedical Research have formed in Boston attracting biotech, pharmaceutical and venture capital firm to translate academic research into new therapies.

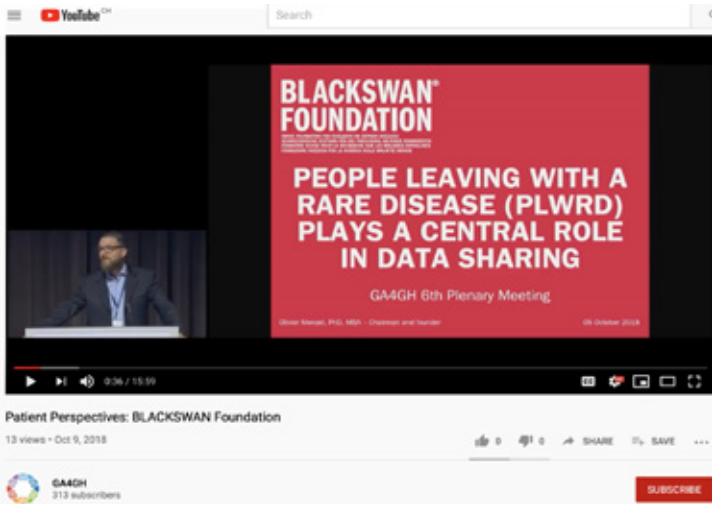
2018 ACTIVITIES
INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

BIOBANKING 2018: EVENT FEATURED INTERNATIONAL AND NATIONAL EXPERTS SHARING THEIR VISION OF THE "BIOBANKING OF THE FUTURE". SWISSTECH CONVENTION CENTER IN LAUSANNE ON THE EPFL CAMPUS.

Three panels of experts discussed new directions in state-of-the-art biobanking research. To meet current requirements, the scientific community biobanks need to tackle challenges including harmonized procedures, promotion of high quality standards or sustainability, all of them in the framework of their ethical, legal and social dimensions. The conference thus provided a forum for discussion around topics on next biobanking generation including focus on optimal usage of biological resources as well as present successful human and non-human biobanking research examples.

BLACKSWAN Foundation was invited to present its vision and how biobanking helps the rare disease community.





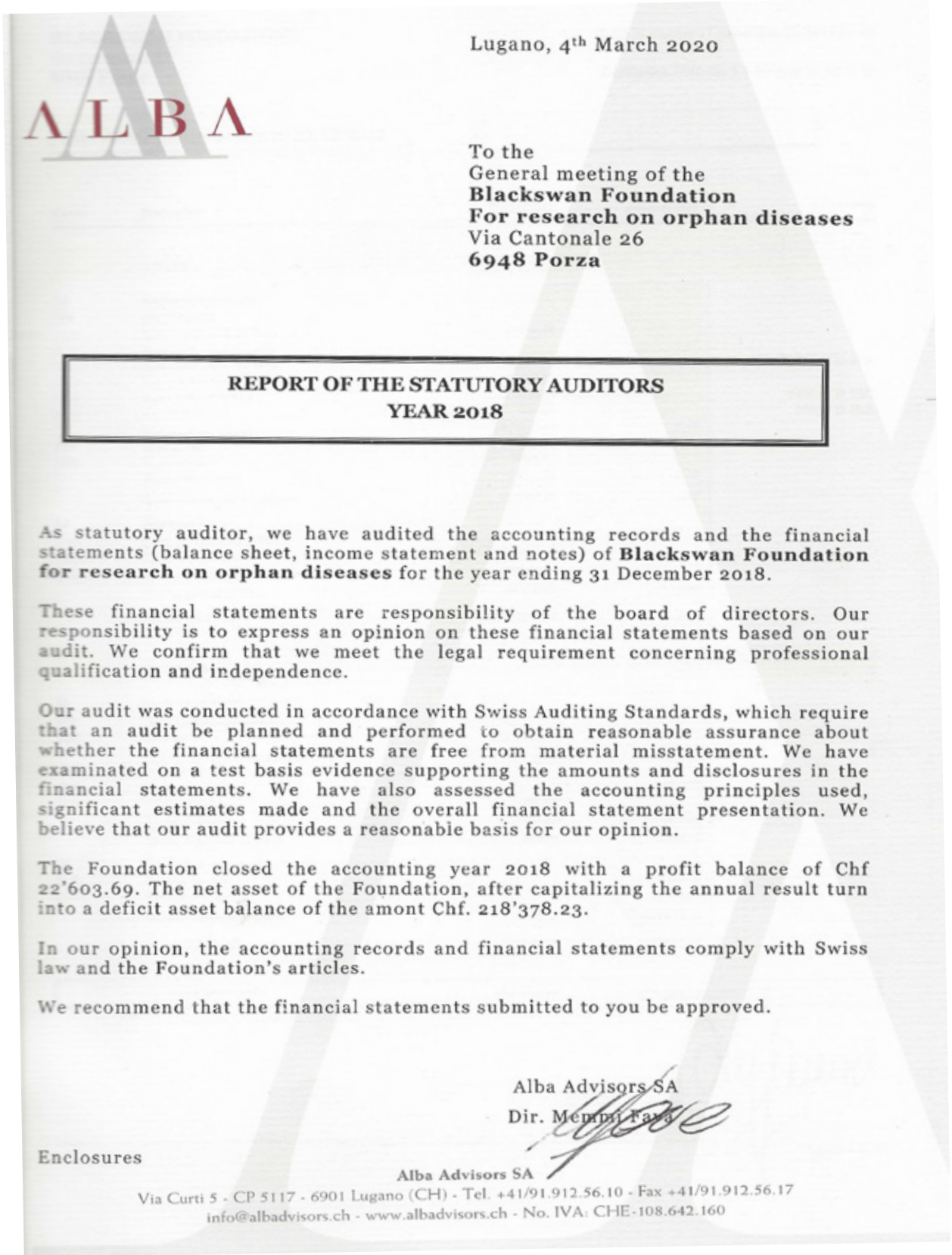
GA4GH 6TH PLENARY MEETING 2018, BASEL

The Global Alliance for Genomics and Health (GA4GH) is an international, nonprofit alliance formed in 2013 to accelerate the potential of research and medicine to advance human health. Bringing together 500+ leading organizations working in healthcare, research, patient advocacy, life science, and information technology, the GA4GH community is working together to create frameworks and standards to enable the responsible, voluntary, and secure sharing of genomic and health-related data.

The GA4GH 6th Plenary Meeting in Basel, Switzerland brought together more than 430 individuals representing more than 200 organizations across 25 countries to learn about new deliverables being developed under GA4GH Connect — a multi-year strategic phase focused on connecting GA4GH development work to the immediate data sharing needs of the genomics and health community. An additional 200+ individuals joined the meeting by live stream on October 4 and 5.

BLACKSWAN Foundation was invited to present its vision and highlight the role that patients and/or patient advocacy groups can play in enabling data sharing, including providing phenotypes, genetic data and genetic test results as well as developing patient registries and recruiting patients into studies that can advance an understanding of disease and move towards treatments.

FINANCIAL REPORT 2018



ALBA

Lugano, 4th March 2020

To the
General meeting of the
Blackswan Foundation
For research on orphan diseases
Via Cantonale 26
6948 Porza

REPORT OF THE STATUTORY AUDITORS
YEAR 2018

As statutory auditor, we have audited the accounting records and the financial statements (balance sheet, income statement and notes) of **Blackswan Foundation for research on orphan diseases** for the year ending 31 December 2018.

These financial statements are responsibility of the board of directors. Our responsibility is to express an opinion on these financial statements based on our audit. We confirm that we meet the legal requirement concerning professional qualification and independence.

Our audit was conducted in accordance with Swiss Auditing Standards, which require that an audit be planned and performed to obtain reasonable assurance about whether the financial statements are free from material misstatement. We have examined on a test basis evidence supporting the amounts and disclosures in the financial statements. We have also assessed the accounting principles used, significant estimates made and the overall financial statement presentation. We believe that our audit provides a reasonable basis for our opinion.

The Foundation closed the accounting year 2018 with a profit balance of Chf 22'603.69. The net asset of the Foundation, after capitalizing the annual result turn into a deficit asset balance of the amont Chf. 218'378.23.

In our opinion, the accounting records and financial statements comply with Swiss law and the Foundation's articles.

We recommend that the financial statements submitted to you be approved.

Alba Advisors SA
Dir. Memmi Fava

Enclosures

Alba Advisors SA
Via Curti 5 - CP 5117 - 6901 Lugano (CH) - Tel. +41/91.912.56.10 - Fax +41/91.912.56.17
info@albadvisors.ch - www.albadvisors.ch - No. IVA: CHE-108.642.160

FINANCIAL REPORT
2018 BALANCE

BLACKSWAN FONDAZIONE
Via Cantonale 26
6948 Porza

Data di stampa 17 settembre 2019/11:27:48

Contabilità 2018 dal 1.1.2018 al 31.12.2018

BILANCIO patrimoniale al 31.12.2018

Conto	Descrizione	Dare (CHF)	Avere (CHF)	Saldo valuta
	ATTIVI			
10	**Sostanza circolante**			
100	***Mezzi liquidi***			
1020	Banca EFG - 007 (Ex AA)	71'746.50		
1021	Banca EFG - 015 (Ex AB)		1.17	
1022	Banca EFG - 031 (Ex MA)	83'204.83		73'840.92 D EUR
1023	Banca EFG - 023 (Ex LA)	10'615.92		
1024	Banca EFG - 058 Us$	9'159.56		9'306.67 D USD
1031	PayPal EUR	657.24		583.23 D EUR
	Totale Mezzi liquidi	*175'384.05*	*1.17*	
109	***Transitori***			
1090	Transitori attivi	5'505.15		
	Totale Transitori	*5'505.15*	*0.00*	
	Totale Sostanza circolante	**180'889.20**	**1.17**	
11	**Sostanza fissa**			
1105	Mobilio e macchine ufficio	890.00		
1106	Hardware e Software	5'300.00		
1200	Attivazione Progetto RARevolution (2016-2019)	35'500.00		
	Totale Sostanza fissa	**41'690.00**	**0.00**	
	Totale ATTIVI	**222'579.20**	**1.17**	
	PASSIVI			
20	**Capitale di terzi**			
200	***Debiti a breve termine***			
2000	Creditori		1'500.75	
	Totale Debiti a breve termine	*0.00*	*1'500.75*	
209	***Transitori***			
2090	Transitori passivi		3'500.00	
2093	Transitorio stipendi	800.95		
	Totale Transitori	*800.95*	*3'500.00*	
	Totale Capitale di terzi	**800.95**	**5'000.75**	
21	**Capitale proprio**			
2150	Risultati riportati		195'774.54	
2170	Risultato d'esercizio		22'603.69	
	Totale Capitale proprio	**0.00**	**218'378.23**	
	Totale PASSIVI	**800.95**	**223'378.98**	
	Totale a pareggio	**223'380.15**	**223'380.15**	

FINANCIAL REPORT
2018 INCOME STATEMENT

BLACKSWAN FONDAZIONE
Via Cantonale 26
6948 Porza

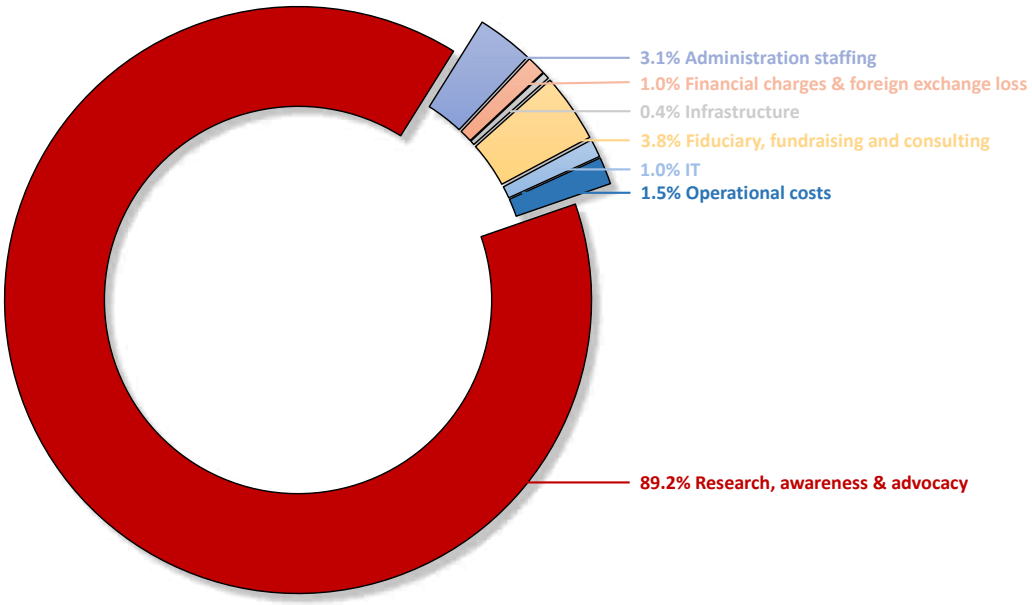
Data di stampa 17 settembre 2019/11:28:15

Contabilità 2018 dal 1.1.2018 al 31.12.2018

CONTO economico dal 1.1.2018 al 31.12.2018

Conto	Descrizione	Dare (CHF)	Avere (CHF)	Saldo valuta
	COSTI PER MATERIALE E MERCI			
	Totale COSTI PER MATERIALE E MERCI	**0.00**	**0.00**	
	COSTI D'ESERCIZIO			
40	**Costi del personale**			
4000	Stipendi e salari	21'600.00		
4010	AVS/AI/IPG	3'296.25		
4020	Assicurazione malattia	868.30		
4030	Assicurazione infortuni	65.70		
4040	Cassa pensione	5'691.90		
4050	Imposte alla fonte	255.50		
	Totale Costi del personale	**31'777.65**	**0.00**	
41	**ALTRI COSTI D'ESERCIZIO**			
4210	Interessi e spese diverse	74.49		
4220	Spese bancarie	624.50		
4250	Differenze di cambio	10'041.48		
4260	Costi operazionali	15'370.56		
4400	Ammortamenti	6'059.05		
4401	Ammortamento progetti	17'750.00		
4700	Materiale ufficio e stampati	3'720.38		
4701	Promozione - stampati	204.00		
4720	Spese telefoniche/fax/postali	39.85		
4760	Spese di rappresentanza	6'332.60		
4770	Costi amministrativi e consulenze	34'708.10		
4771	Tasse, Fiduciaria, membership	4'030.71		
4802	Sito web e webmaster	10'224.34		
4830	RE(ACT) congress	78'846.50		
4831	RE(ACT) Community	48'834.65		
4832	RDI (Rare Disease International)	98'000.00		
4890	Altri costi d'esercizio		36.62	
5000	Grants	662'862.72		
	Totale Altri costi d'esercizio	**997'723.93**	**36.62**	
	Totale COSTI D'ESERCIZIO	**1'029'501.58**	**36.62**	

FINANCIAL REPORT
2018 EXPENSES OVERVIEW



NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2018

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.

The only employee, Mrs. Chiara Ciriminna Swan (Project Coordinator & External Relations) paid by the Foundation serves on the Board only in an advisory capacity and have no voting rights. Moreover, her salary was covered by unrestricted donations dedicated to support the "administrative costs" 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.

FINANCIAL REPORT
2018 INCOME STATEMENT

BLACKSWAN FONDAZIONE
Via Cantonale 26
6948 Porza

Data di stampa 17 settembre 2019/11:28:15

Contabilità 2018 dal 1.1.2018 al 31.12.2018

CONTO economico dal 1.1.2018 al 31.12.2018

Conto	Descrizione	Dare (CHF)	Avere (CHF)	Saldo valuta
	RICAVI D'ESERCIZIO			
60	**Ricavi da vendite**			
600	***Ricavi da vendite***			
6001	Registrazioni RE(ACT) congress		8'097.31	
6002	Donazioni RE(ACT) community		7'186.02	
6004	Donazioni libri ricette		1'410.00	
6006	Donazioni PayPal		1'408.94	
6008	Donazioni varie		968'972.11	
6010	Donazioni progetto RAREvolution		62'221.87	
6013	Sponsoring RE (ACT) Congress		2'556.58	
6014	Rimborsi		215.82	
	Totale Ricavi da vendite	*0.00*	*1'052'068.65*	
	Totale Ricavi da vendite	**0.00**	**1'052'068.65**	
	Totale RICAVI D'ESERCIZIO	**0.00**	**1'052'068.65**	
	Risultato d'esercizio	*22'603.69*		
	Totale a pareggio	**1'052'105.27**	**1'052'105.27**	

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
- 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

BOARD OF DIRECTORS

CHAIRMAN AND FOUNDER

Dr OLIVIER MENZEL, PhD, MBA;
Vuarrens, Switzerland

MEMBERS

VINCENZO PIANTEDOSI, Retired Banking Executive;
Nassau, Bahamas
MASSIMO RICCARDI, Studio Legale Riccardi;
Lugano, Switzerland

ADVISORY BOARD

CHIARA CIRIMINNA SWAN, Program Manager & External Relations; Lausanne
SKANDER NAJAR, Strategy & Marketing; Geneva
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
EFG Bank SA
Via Magatti 2
6900 Lugano, Switzerland

IBAN: CH5208667007280511007 (Donation in CHF)
IBAN: CH8308667007280511031 (Donation in Euro)
IBAN: CH3308667007280511058 (Donation in USD)

SWIFT: EFGBCHZZ
SIC: 086673
Clearing: 8667

DONATION BY SMS (SWITZERLAND ONLY)
DONATION BY SMS TO 339
BS followed with an amount
(i.e. for an immediate donation of 100 CHF,
send BS 100 to 339).

CONTACT

BLACKSWAN Foundation
Chemin de la Riaz 11
1418 Vuarrens - Switzerland
Infoline: +41 21 887 64 34
contact@blackswanfoundation.ch

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

FACEBOOK
www.facebook.com/Blackswan.Foundation
www.facebook.com/REACT.community.official

TWITTER
twitter.com/blackswanfound
twitter.com/react_community

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

INSTAGRAM
instagram.com/blackswan_foundation/

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