Rapport Annuel

Annual Report

2017

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

2017 est une année importante pour la Fondation BLACKSWAN et pour le milieu de la recherche afin que les maladies rares deviennent une priorité mondiale en matière de santé et de recherche.

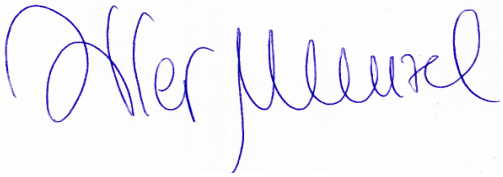
A la Fondation BLACKSWAN, nous pensons qu'un engagement plus fort au niveau international est fondamental pour attirer plus de ressources, créer de nouvelles incitations pour la recherche et développer des thérapies pour des millions de patients. C'est pourquoi, en 2017, la Fondation a co-organisé avec Rare Diseases International (RDI - l'alliance mondiale des personnes vivant avec une maladie rare de toutes nationalités et représentant toutes maladies rares) un événement unique en son genre à Genève qui a réuni des experts internationaux dans les domaines de la santé publique, des droits humains, de la recherche scientifique, du plaidoyer des patients et du secteur de la santé pour discuter pourquoi et comment les maladies rares devraient figurer dans le programme de santé mondial.

L'événement s'est concentré sur le rôle crucial que joue la collaboration internationale dans la promotion des maladies rares en tant que priorité mondiale en matière de santé publique et de recherche, conformément à l'esprit du Programme des Nations Unies pour le développement durable 2030, à savoir « ne laisser personne pour compte « (‘leaving no one behind’).

À la Fondation BLACKSWAN, nous croyons fermement que la collaboration de toutes les parties prenantes pour montrer l'importance des maladies rares dans l'agenda de la santé amènera les organisations internationales, comme l'OMS et d'autres agences des Nations Unies, à reconnaître les maladies rares comme une priorité de santé publique et de recherche et à sauver la vie de millions de personnes.

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 6 projets internationaux, 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 2 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.



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

2017 is an important year for the BLACKSWAN Foundation and for the research community to advocate internationally making rare diseases a global health and research priority.

At the BLACKSWAN Foundation we believe that a stronger engagement at international level is fundamental to attract more resources, create new incentives for research and develop therapies for millions of patients. For this reason, in 2017 the Foundation co-organized with Rare Diseases International (RDI - the global alliance of people living with a rare disease of all nationalities across all rare diseases) a-first-of-its-kind event in Geneva which brought together international experts in the fields of public health, human rights, scientific research, patient advocacy and the health industry to discuss why and how rare diseases should be part of the global health agenda.

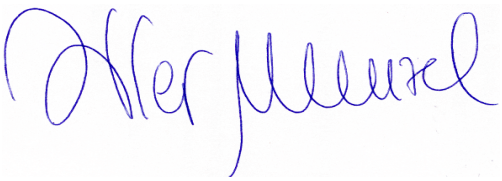
The event focused on the crucial role international collaboration plays in promoting rare diseases as a global public health and research priority, in line with the spirit of the United Nations' 2030 Sustainable Development Agenda of 'leaving no one behind'.

At the BLACKSWAN Foundation we strongly believe that the collaboration of all stakeholders in showing the importance of rare diseases on the health agenda will bring international organizations, such as the WHO and other United Nations agencies, to recognize rare diseases as a public health and research priority and save the life of millions of individuals.

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 regular base. This resulted in financing 6 international projects, has prevented to support similar projects where we could ask scientists to collaborate. After 2 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 a treatment to our young children.

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

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 ?

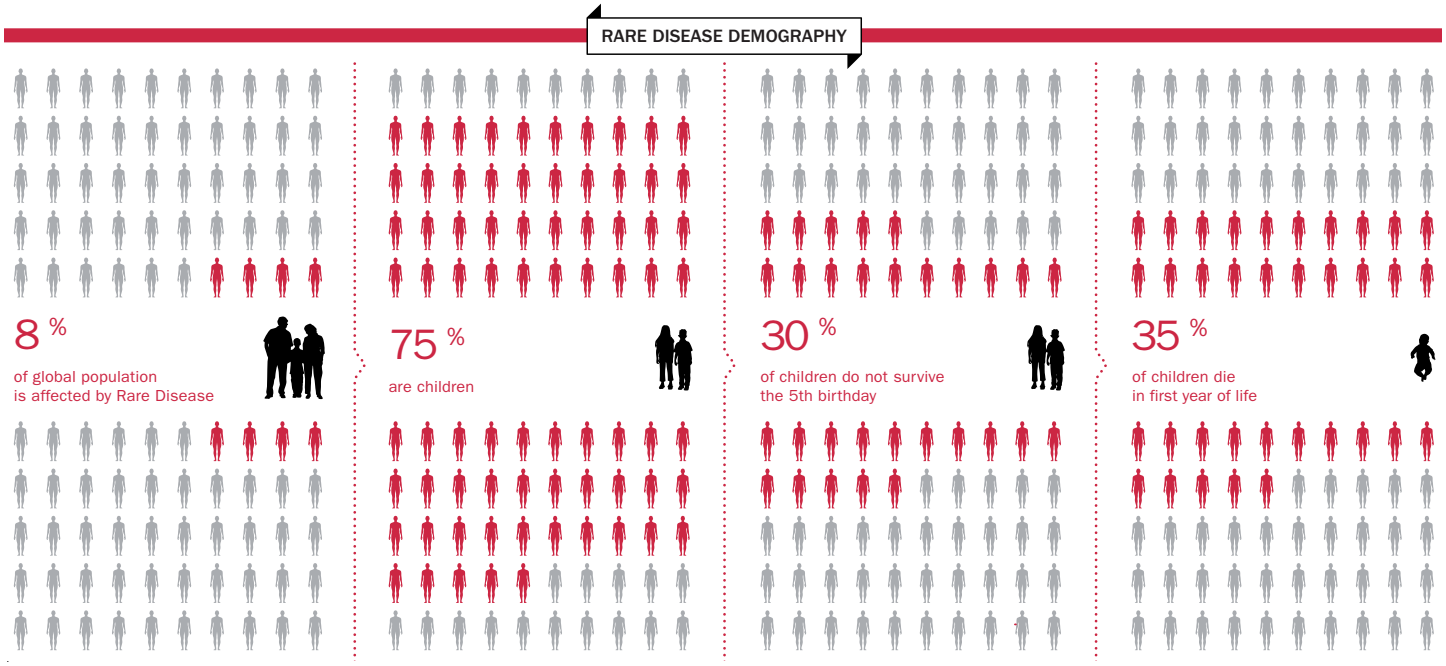
A disease or disorder is defined as rare in Europe and in Switzerland when it affects not more than 1 in every 2,000 persons. These conditions are generally chronic, progressive, debilitating and often life-threatening. In addition, these rare diseases present certain challenges for the development of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

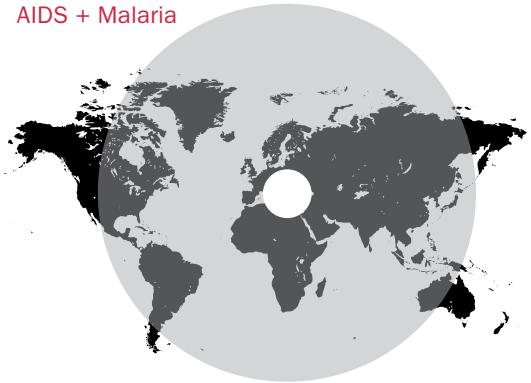
RARE DISEASES GLOBAL IMPACT

475 MIO/7'052 MIO

RARE Diseases

228 MIO/7'052 MIO

AIDS + Malaria



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

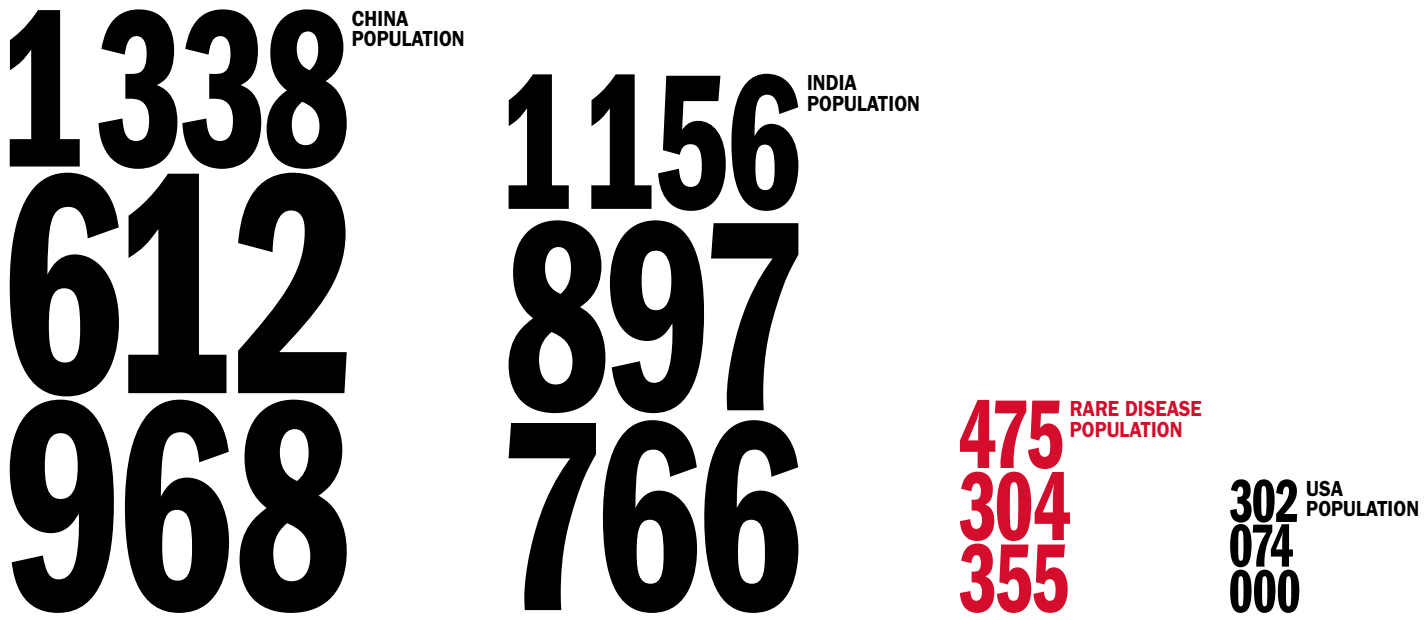
THE FOUNDATION IN BRIEF

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.



2017 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

in english only

IIn 2017, BLACKSWAN Foundation efforts to support scientific research focused on the consolidation of the online platform, the RE(ACT) Community. The community is conceived to help researchers working in the field of rare and orphan diseases to create new collaborations, share knowledge and promote their scientific projects.

The main objective of the RE(ACT) Community is to increase international cooperation on rare disease's research worldwide and thus accelerating the delivery on the market of new molecules and therapies for millions of patients.

The Community also encourages the creation of a society of researchers that can raise awareness about the needs of this sector, emphasizes the results achieved to gaining stronger political leverage and ask for more support from public institutions.

The online platform is organized around four main axes: Meet, Learn, Share and Support. Meet other researchers and find new collaborations; Learn from the knowledge and experience of other researchers and patients; Share scientific knowledge and facilitate the exchange of information between researchers and patients. It also offers the possibility to financially support research projects by starting a crowdfunding campaign on its website.

Gene therapy using CRiSPR/Cas9 technology and AAV9 system in FOXG1 iPSCs-derived neurons. In 2017, 154,000 Euro have been crowdfunded via the RE(ACT) Community for a research team based at the University of Siena.

The project team will use CRiSPR/Cas9 technology on FOXG1 patients' stem cells (and cut the mutated allele entirely and replace it with a healthy gene. To allow the CRiSPR/Cas9 correction system to enter the cells, a viral system (AAV = Adeno-Associated Virus) will be used as carriers. The team plans on doing this to an ex-vivo model (human patient-derived iPSCs, from skin biopsies), in order to prove the efficiency and safety of the method.

2017 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

THE RIGHT TO HEALTH – MAKING RARE DISEASES A GLOBAL HEALTH AND RESEARCH PRIORITY

Held to mark the occasion of Rare Disease Day 2017, the event was organized in partnership with Rare Diseases International and EURORDIS-Rare Diseases Europe.

A-first-of-its-kind event takes place in Geneva to bring together international experts in the fields of public health, human rights, scientific research, patient advocacy and the health industry to discuss why and how rare diseases should be part of the global health agenda.

Over 150 participants at the Rare Diseases International policy event 'The Right to Health: The Rare Disease Perspective' are exploring ways to address inequality and improve access to health for the estimated 300 million people living with a rare disease around the world.

The event focused on the crucial role international collaboration plays in promoting rare diseases as a global public health and research priority, in line with the spirit of the United Nations' 2030 Sustainable Development Agenda of 'leaving no one behind'. Participants discussed how this international cooperation is vital to incentivize research and innovation, to increase access to diagnostics, medicines and treatments, and to ensure rare diseases are integrated into Sustainable Development Goal (SDG) number three to 'ensure healthy lives and promote well-being for all at all ages'.

The event was organized in the wake of the third International Rare Disease Research Consortium (IRDiRC) Conference in Paris.

Discussions were built on the IRDiRC goals, as well as the 2030 Sustainable Development Agenda, the conclusions of the UN High-Level Panel on Access to Medicines, a statement made by Administrator of the UN Development Program Helen Clark, and the work of the recently launched NGO Committee for Rare Diseases, which is committed to catalyzing all efforts towards the delivery of the UN SDGs in support of rare diseases.

Key speakers at the event include:

- Christopher P. Austin, Chair, International Rare Disease Research Consortium (IRDiRC), National Institutes of Health, USA
- Peter Beyer, Senior Advisor, Public Health, Innovation and Intellectual Property, Department of Essential Medicines and Health Products, World Health Organization
- Ruth Dreifuss, Co-Chair of the United Nations Secretary General's High-level Panel on Access to Medicines, former President of the Swiss Confederation
- Dainius Puras, United Nations Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Office of the UN High Commissioner for Human Rights
- Maria Luisa Silva, Director of UN Development Program (UNDP) Office in Geneva

Patient representatives from around the world also participated to illustrate the importance of patient input in efforts to make rare diseases a global health priority:

- Hawa Dramé, Founder, Fondation Internationale Tierno et Mariam (FITIMA), Burkina Faso and Guinea
- Christina Fasser, President, Retina International & Vice-Chair, ProRaris
- Jim Green, President, International Niemann-Pick Disease Alliance
- Ramaiah Muthyala, Founder & President, Indian Organization for Rare Diseases
- Durhane Wong-Rieger, President and CEO, Canadian Organization for Rare Disorders; Chair, Rare Diseases International

The event was under the patronage of the Federal Councilor Alain Berset, Head of the Swiss Federal Department of Home Affairs, and with the participation of the International Rare Diseases Research Consortium, the NGO Committee for Rare Diseases, Orphanet and ProRaris.

2017 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

FOXG1 RESEARCH TEAM

FOXG1 Syndrome is a neurological disorder caused by a mutation in the FOXG1 gene, similar to RETT Syndrome. Previously called Brain Factor 1, FOXG1 is one of the first and most essential genes formed during human development. FOXG1 builds the Cerebrum – which controls cognition. Affected patients in most cases, cannot sit, walk, talk and eat without a feeding tube. 87% are epileptic and pharma-resistant.

FOXG1 Research is a special team created within the BLACKSWAN Foundation that supports research on FOXG1 syndrome. In collaboration with the Foundation, the FOXG1 Research team works to raise funds and establish a network of researchers who work synergistically to identify innovative therapeutic strategies for FOXG1 syndrome.

The FOXG1 research team's mission is to:

- Collect funds for FOXG1 research projects
- Provide grants for research project on FOXG1
- Find a cure for all FOXG1 children in the world (all ages, all types of mutations, all geographies)
- Provide equal access to a cure for ALL FOXG1 children in the world

FEASIBILITY STUDY FOR THE "SWISS CENTRE FOR THERAPEUTICS DISCOVERY" (SCTD)

BLACKSWAN Foundation conducted in 2017 a feasibility study for the creation of a unique structure for therapeutics development in rare and orphan diseases.

The center will be a no-profit open innovation platform dedicated to translational science on rare diseases. Founding members will be the Swiss Universities, Federal institutes of technology, Hospitals and patient associations under the patronage of the Swiss Confederation. Universities, research institutes, foundations or patient associations outside Switzerland interested to translational research and development can participate as fellow founders.

A feasibility study will show how the innovative research project justifies the support of donations. For this purpose, the BLACKSWAN Foundation has an external consultant engaged in order to acquire a number of answers which is a specialist in fundraising and he should present the project and our vision to selected personalities and ask them for their opinion.

The aim of the study is therefore to find out what the chances of attracting donors are and what concrete measures need to be taken in order to inspire them to donate for this project. Results expected beginning of 2018.

2017 ACTIVITIES
INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

LE LIONS CLUB HORIZON DE LAUSANNE AIDE LA RECHERCHE EN ORGANISANT UN REPAS DE SOUTIEN

Le Lions Club Lausanne – Horizons, club mixte tout nouvellement créé en 2016 a organisé sa première action sous forme de repas de soutien le 26 avril 2016 au Carlton Hôtel.
Ce repas s'est déroulé avec un concert de l'Association POURQUOI PAS qui a enchanté les convives.
Dans le cadre de sa mission, le Dr. Olivier Menzel a reçu le montant récolté (CHF 6'000) lors de cet événement.

12TH ANNUAL ICORD MEETING, 7-10 SEPTEMBER 2017, BEIJING, CHINA

BLACKSWAN Foundation was invited to present its actions at the international conference on rare diseases and orphan drugs (ICORD) in Beijing.
ICORD, the Chinese Organization for Rare Diseases (CORD) and Peking Union Medical College Hospital (PUMCH), three non-profit entities, co-organized the 12th Annual ICORD Meeting with Rare Diseases International (RDI) as an international partner. The meeting took place together with the 6th China Rare Disease Summit 7-10 September 2017 at the Beijing JW Marriott Hotel in the fascinating and historical city of Beijing, China.
The 12th ICORD Annual Conference/6th China Rare Diseases Summit was jointly organized by ICORD, CORD (Chinese Organization for Rare Disorders) and PUMCH (Peking Medical Union College Hospital). It was successfully held in Beijing on 7-10 September 2017.
With 700+ attendees from 20+ countries around the world, this was the biggest rare disease conference ever held in China. Over 100 distinguished speakers presented at 20 sessions. The conference also attracted broad media interests, with 49 reporters providing coverages at and after the conference.

FINANCIAL REPORT 2017

ALBA

Lugano, 6th September 2018

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

REPORT OF THE STATUTORY AUDITORS YEAR 2017

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 2017.

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 2016 with a deficit balance of Chf 16'502.70. The net asset of the Foundation, after capitalizing the annual result turn into a deficit asset balance of the amont Chf. 195'774.54.

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 2017 BALANCE

Via Cantonale 26
6948 Porza

Contabilità 2017 dal 1.1.2017 al 31.12.2017

BILANCIO patrimoniale al 31.12.2017

Conto	Descrizione	Dare (CHF)	Avere (CHF)	Saldo valuta
	ATTIVI			
10	**Sostanza circolante**			
100	***Mezzi liquidi***			
1020	Banca EFG - 007 (Ex AA)	42'042.96		
1021	Banca EFG - 015 (Ex AB)	680.88		
1022	Banca EFG - 031 (Ex MA)	41'353.13		37'264.42 D EUR
1023	Banca EFG - 023 (Ex LA)	29'895.95		
1024	Banca EFG - 058 Us$	21'292.66		21'625.41 D USD
1030	PayPal	119.70		
1031	PayPal EUR	10'718.76		9'613.22 D EUR
	Totale Mezzi liquidi	*146'104.04*	*0.00*	
109	***Transitori***			
1090	Transitori attivi	820.45		
1093	Transitorio Carta di credito		800.00	
	Totale Transitori	*820.45*	*800.00*	
	Totale Sostanza circolante	**146'924.49**	**800.00**	
11	**Sostanza fissa**			
1105	Mobilio e macchine ufficio	3'390.00		
1106	Hardware e Software	5'830.00		
1200	Attivazione Progetto RARevolution (2016-2019)	53'250.00		
	Totale Sostanza fissa	**62'470.00**	**0.00**	
	Totale ATTIVI	**209'394.49**	**800.00**	

Conto	Descrizione	Dare (CHF)	Avere (CHF)	Saldo valuta
	PASSIVI			
20	**Capitale di terzi**			
200	***Debiti a breve termine***			
2000	Creditori		10'420.90	
	Totale Debiti a breve termine	*0.00*	*10'420.90*	
209	***Transitori***			
2090	Transitori passivi		3'200.00	
2093	Transitorio stipendi	800.95		
	Totale Transitori	*800.95*	*3'200.00*	
	Totale Capitale di terzi	**800.95**	**13'620.90**	
21	**Capitale proprio**			
2150	Risultati riportati		212'277.24	
2170	Risultato d'esercizio	16'502.70		
	Totale Capitale proprio	**16'502.70**	**212'277.24**	
	Totale PASSIVI	**17'303.65**	**225'898.14**	
	Totale a pareggio	**226'698.14**	**226'698.14**	

FINANCIAL REPORT
2017 INCOME STATEMENT

BLACKSWAN FONDAZIONE
Via Cantonale 26
6948 Porza

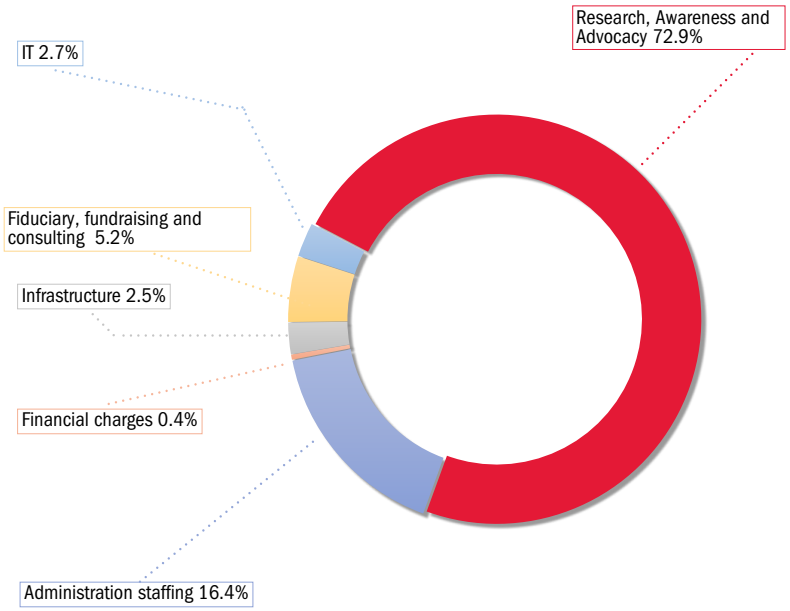
Data di stampa 4 maggio 2018/14:15:3

Contabilità 2017 dal 1.1.2017 al 31.12.20

CONTO economico dal 1.1.2017 al 31.12.2017

Conto	Descrizione	Dare (CHF)	Avere (CHF)	Saldo valu
	COSTI D'ESERCIZIO			
40	**Costi del personale**			
4000	Stipendi e salari	33'600.00		
4010	AVS/AI/IPG	14'827.80		
4020	Assicurazione malattia	1'439.90		
4030	Assicurazione infortuni	403.00		
4040	Cassa pensione	8'581.20		
4050	Imposte alla fonte		548.15	
	Totale Costi del personale	**58'851.90**	**548.15**	
41	**ALTRI COSTI D'ESERCIZIO**			
4210	Interessi e spese diverse	603.23		
4220	Spese bancarie	820.89		
4250	Differenze di cambio	50.28		
4700	Materiale ufficio e stampati	8'389.60		
4701	Promozione - stampati	560.15		
4703	Spese Gala	2'820.00		
4704	Promozione e marketing	70.00		
4720	Spese telefoniche/fax/postali	590.00		
4760	Spese di rappresentanza	7'103.17		
4770	Costi amministrativi e consulenze	13'613.24		
4771	Tasse, Fiduciaria, membership	5'066.99		
4801	Pubblicità e materiale REACT	1'969.23		
4802	Sito web e webmaster	9'670.72		
4811	Contributi alla ricerca	44'462.76		
4815	Spese progetto RAREvolution	50'000.00		
4830	RE(ACT) congress	14'053.74		
4831	RE(ACT) Community	63'127.52		
4832	RDI (Rare Disease International)	78'000.00		
	Totale Altri costi d'esercizio	**300'971.52**	**0.00**	
	Totale COSTI D'ESERCIZIO	**359'823.42**	**548.15**	

FINANCIAL REPORT
2017 EXPENSES OVERVIEW



NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2017

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
2017 INCOME STATEMENT

BLACKSWAN FONDAZIONE
Via Cantonale 26
6948 Porza

Data di stampa 4 maggio 2018/14:15:39

Contabilità 2017 dal 1.1.2017 al 31.12.2017

CONTO economico dal 1.1.2017 al 31.12.2017

Conto	Descrizione	Dare (CHF)	Avere (CHF)	Saldo valuta
	RICAVI D'ESERCIZIO			
60	**Ricavi da vendite**			
600	***Ricavi da vendite***			
6002	Donazioni RE(ACT) community		1'111.57	
6006	Donazioni PayPal		13'864.13	
6008	Donazioni varie		193'330.29	
6010	Donazioni progetto RAREvolution		97'081.00	
6012	Donazioni Gala/Eventi		2'260.00	
6013	Sponsoring RE (ACT) Congress		35'125.58	
	Totale Ricavi da vendite	*0.00*	*342'772.57*	
	Totale Ricavi da vendite	**0.00**	**342'772.57**	
	Totale RICAVI D'ESERCIZIO	**0.00**	**342'772.57**	
	Risultato d'esercizio		***16'502.70***	
	Totale a pareggio	**359'823.42**	**359'823.42**	

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

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Vuarrens, Switzerland

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DONATIONS

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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
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www.react-congress.org

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FOUNDATION

SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASE S
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FONDATION SUISSE POUR LA RECHERCHE SUR LES MALADIES ORPHELINE S
FONDAZIONE SVIZZERA PER LA RICERCA SULLE MALA TTIE ORFANE