Rapport Annuel

Annual Report

2019

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 2019, la Fondation BLACKSWAN a connu un énorme succès au niveau international.

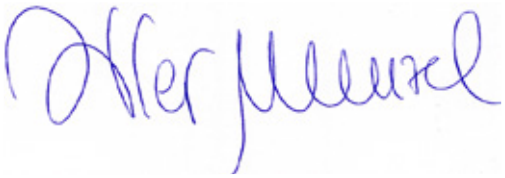
Pour la première fois, nous avons organisé notre cinquième congrès « RE(ACT) Congress » en dehors de l'Europe, en Amérique du Nord, avec la prestigieuse collaboration de l'Office américain de recherche sur les maladies rares (ORDR) au sein du National Center for Advancing Translational Sciences (NCATS) du National Institutes of Health (NIH) et du Centre hospitalier pour enfants de l'Est de l'Ontario (CHEO), en partenariat avec l'Organisation canadienne pour les maladies rares (CORD), les Instituts de recherche en santé du Canada (IRSC) et Genome Canada.

La Fondation BLACKSWAN a été choisie comme partenaire et elle est soutenue par le nouveau programme européen commun sur les maladies rares (European Joint Programme on Rare Diseases - EJP RD). Le programme européen sur les maladies rares (EJP RD) réunit plus de 130 institutions (dont les 24 réseaux de référence européens) de 35 pays afin de créer un écosystème complet et durable permettant un cercle vertueux entre la recherche, les soins et l'innovation médicale. Le rôle central de la Fondation au sein du programme européen sur les maladies rares sera d'aider à la communication, à la diffusion et à la collaboration scientifiques.

À la Fondation BLACKSWAN, nous croyons fermement que les collaborations internationales, la coopération structurée entre les organisations de patients et les projets scientifiques sont indispensables pour maximiser la rareté des ressources destinées à la recherche.

De plus, montrer l'importance des maladies rares dans l'agenda de la santé amènera les organisations internationales à reconnaître les maladies rares comme une priorité de santé publique et de recherche et à sauver la vie de millions d'individus.

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

In 2019 the BLACKSWAN Foundation had a huge highlight at the international level.

For the first time, we organized our fifth RE(ACT) Congress outside Europe, in North America, with the prestigious collaboration of the US Office of Rare Diseases Research (ORDR) within the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health (NIH) and the Children's Hospital of Eastern Ontario (CHEO), in partnership with the Canadian Organization for Rare Disorders (CORD), the Canadian Institutes of Health Research (CIHR) and Genome Canada.

The BLACKSWAN Foundation has been chosen as a partner and supported by the newly established European Joint Programme on Rare Diseases (EJP RD). The European Joint Programme on Rare Diseases (EJP RD) brings over 130 institutions (including all 24 European Reference Networks) from 35 countries to create a comprehensive, sustainable ecosystem allowing a virtuous circle between research, care, and medical innovation. The central role of the Foundation within the EJP RD will be to help the scientific communication, dissemination, and collaboration.

At the BLACKSWAN Foundation, we firmly believe that international collaborations, structured cooperation among patient organizations, and scientific projects are mandatory to maximize the scarcity of resources for research.

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 ?

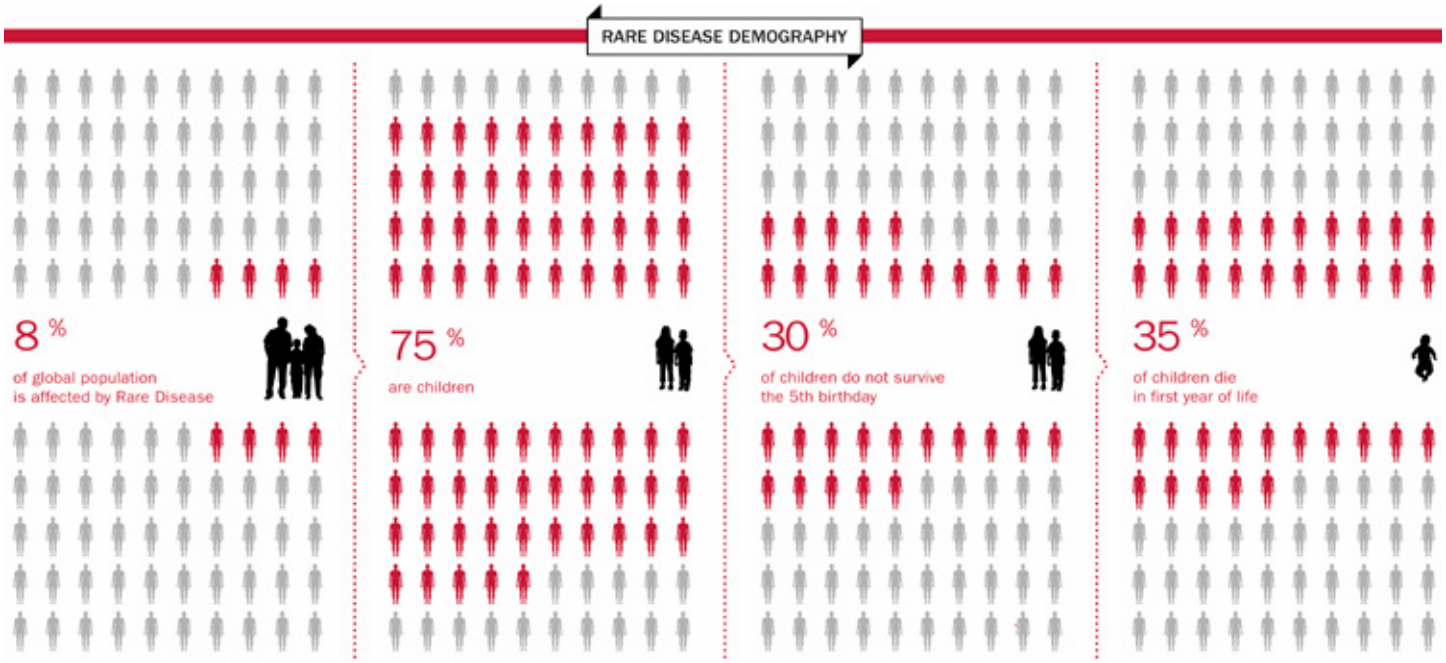
A disease or disorder is defined as rare in Europe and Switzerland when it affects not more than 1 in every 2,000 persons. These conditions are generally chronic, progressive, debilitating, and often life-threatening. In addition, these rare diseases present specific challenges for the development of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

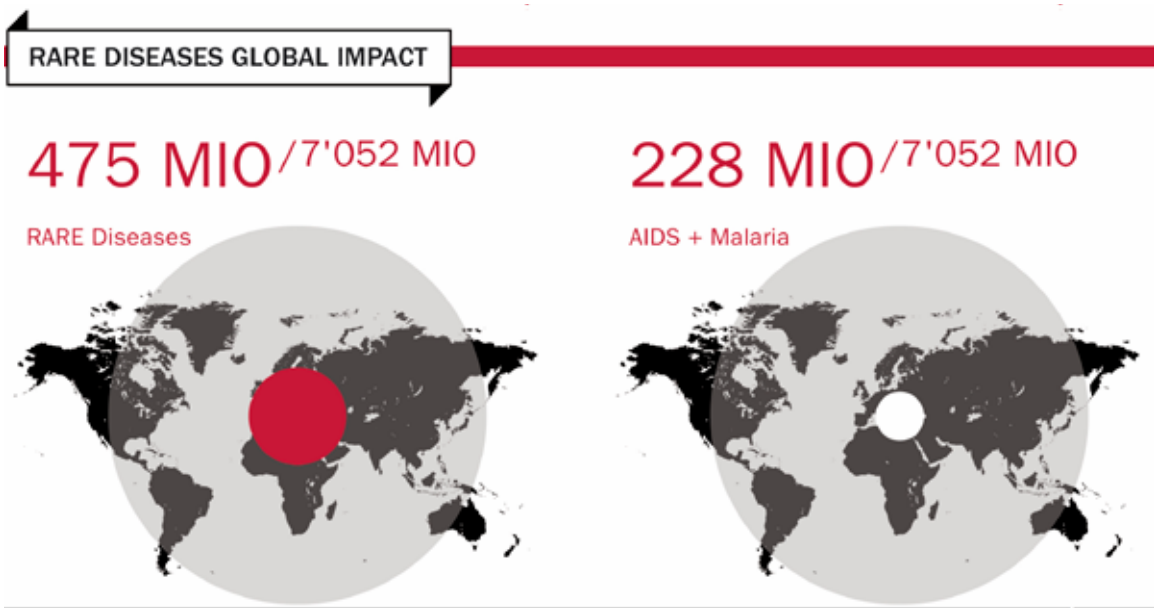
> Financial barriers: National public funding agencies are not proactive in supporting research because of the lack of expertise of international project assessment boards and of the limited number of scientific publications by researchers requesting funding.

> 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 cinq éditions, plus de 1500 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 five editions, more than 1,500 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

2019 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

in english only

1. **Investigation in different brain cells types of FOXG1's role in the regulation of brain energy metabolism and its mitochondrial activity. The proposed project intends to investigate the effect of FOXG1 downregulation by siRNA in primary astrocytes metabolism, mitochondrial activity, neuroprotection, and synaptic plasticity. If a clear link were to be established between FOXG1 activity and brain energy metabolism, the next step would include the test of GliaPharm's proprietary molecules that stimulate brain energy metabolism in FOXG1 transgenic mice.**

PI: Professor Pierre Magistretti, GliaPharm SA, Geneva

Budget: CHF 50'619

2. **Generation of patient-derived FOXG1-mutant iPSCs and isogenic lines using CRISPR/Cas9**

PI: Dr Alysson Mutori, University of California San Diego (UCSD)

Budget: USD 80'000 of USD 209'000 (Collaborative funding with the FOXG1 Research Foundation)

2019 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

TTHE RE(ACT) CONGRESS AMERICA 2019 – INTERNATIONAL CONGRESS OF RESEARCH ON RARE AND ORPHAN DISEASES

We amplify collective action for research on rare diseases #RAREvolution

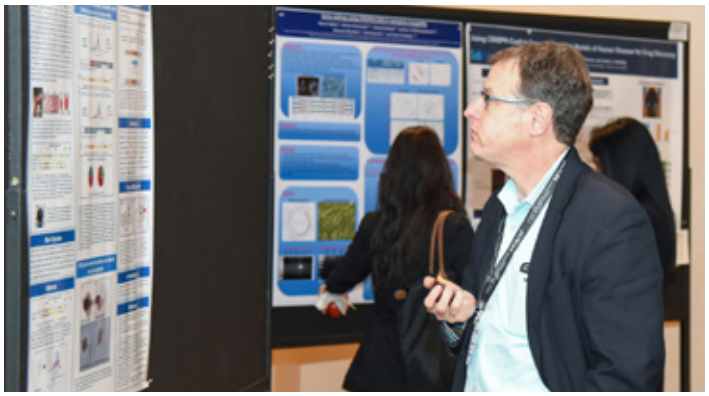
The fifth edition, and the first one held in North America, of the RE(ACT) Congress – International Congress of Research on Rare and Orphan Diseases – was held at the Sheraton Centre Toronto Hotel in Toronto, Canada, from 8-10 May 2019. It was organized by the BLACKSWAN Foundation in collaboration with the Office of Rare Diseases Research (ORDR) within the National Center for Advancing Translational Sciences (NCATS) at the National Institutes of Health (NIH) and the Children's Hospital of Eastern Ontario (CHEO), in partnership with the Canadian Organization for Rare Disorders (CORD), the Canadian Institutes of Health Research (CIHR) and Genome Canada. The Congress also benefited from the support of IRDiRC, Rare Diseases International, Eurordis and Genome Canada.

The event attracted around 150 attendees, including scientists, physicians, patient organizations, pharmaceutical industry representatives and start-ups, patients, and other international stakeholders. During the three-day conference these world-class speakers and participants shared their experiences and presented their innovative and outstanding scientific research on rare diseases. The full list of speakers is available at: http://www.react-congress.org/speakers/.

In his opening speech, Dr. Christopher Austin, Director of NCATS at the NIH, highlighted the importance and unique focus of the Congress which, aligned with the BLACKSWAN Foundation's mission, aims to amplify the collective efforts and voices in rare diseases research.

2019 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

Topics discussed at the congress involved, among others, new developments in stem cells, regenerative medicine, and gene and cell therapies for rare diseases, new methods and tools to study these diseases, insights and lessons gained from indigenous populations, and a joint collaborative session with CORD concluded the RE(ACT) Congress. In this session, patients and family members recounted their experiences and success stories in progressing towards the treatment of their specific diseases. Over the course of the meeting, two dedicated workshops on multi-national clinical trials/registries and generalizable therapeutic approaches for rare diseases provided an overview of collaborative projects dedicated to the scientific community.



2019 ACTIVITIES
INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

COLLÈGE DU LÉMAN ORGANIZED A CHARITY CONCERT IN SUPPORT OF THE BLACKSWAN FOUNDATION: DANIEL LOZAKOVICH'S VIOLIN CONCERT, SUNDAY 5TH MAY 2019 AT THE VICTORIA HALL, GENÈVE

The BLACKSWAN Foundation was on the spotlight at the private violin concert organized by the Collège du Léman with the boarding student Daniel Lozakovich. All funds raised have been donated to our Foundation.
Daniel Lozakovich's majestic music-making has left critics and audiences spellbound. "Perfect mastery. An exceptional talent," observed Le Figaro after a recent performance, while the Boston Globe praised the "poise, tonal purity, and technique to spare" of his debut with the Boston Symphony Orchestra and Andris Nelsons at Tanglewood.
Daniel Lozakovich had his album produced by Deutsche Grammophon and he is studying his last semester at Collège du Léman. The concert has been his salute to the school.

EUROPEAN JOINT PROGRAMME RARE DISEASES GENERAL ASSEMBLY ON THE 17TH, 18TH AND 19TH OF SEPTEMBER 2019 IN GDANSK, POLAND

The EJP RD first General Assembly – Consortium meeting took place on 17 - 19 September in Gdansk, Poland. It was the first occasion for partners to meet and discuss EJP RD activities. This 3-days meeting has been an extremely important opportunity for all EJP RD members to strength internal cooperation, define new cross-collaborations between the members and institutions, and consolidate activities and projects for the upcoming year.
The consortium validated the working plan for the second year of the project and all EJP RD members confirmed their high commitment and motivation. Following the GA meeting, the Annual Work Plan Year 2 of the EJP RD was submitted to the EC.

2019 ACTIVITIES
INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

VALUE CREATION IN PRECISION MEDICINE : ACKNOWLEDGING THE NEED TO DEVISE NEW WAYS TO MEASURE THE VALUE OF HEALTHCARE. ORGANIZED BY HEALTH 2030 & IRGC@EPFL WORKSHOP AT THE BROCHER FOUNDATION; 4-6 DECEMBER 2019

Over the course of the workshop, participants discussed ways of assessing value creation by precision medicine to better manage risks and harness benefits, with the objective of recommending:

1. Major principles and initiatives,

2. How industry, payers (insurers) and regulators can adapt their policies and practices, considering two broad types of payment and medical systems: centralized and public or public/private (for example: UK or France), and decentralized and private or private/public (for example: Switzerland or the USA).

3. Specific application to Switzerland, focusing in particular to the suggestion and possible ways to incentivize and reward diagnostic and prevention.

Abstract of the submitted paper:

In recent years, the development of many pharmaceuticals has taken a precision-oriented approach. Several new medicines promise potential relief in rare genetic diseases and cancer forms that cannot be addressed through traditional treatment methods. While genetic research clarifies the medical potential of precision drugs, a key question arises on how we create value from precision medicine, and how this impact on the governance of pharmaceuticals. We propose a new model of pharmaceutical governance to conceptualize on the value creation from precision drugs. We argue that governing precision drugs is a complex problem that requires collaborative governance of private and public as well as national and international actors. Against the background of nationally-oriented health systems, governance of precision medicine pharmaceuticals has to deal with five specific challenges: 1. coordination of payers and providers, 2. patient empowerment and technology adoption, 3. new research integrating both clinical and genetic data, 4. adoption of alternative assessments of health technology, and, 5. alignment of research and development with payers' perspectives. The contents of this article are based on the outcome of an international workshop with participants from research and medical practice, international and national organizations as well as private companies.

BLACKSWAN Foundation was invited to present its vision and highlight the role that patients and/or patient advocacy groups can play in a better care management and in developing a personalized medicine strategy.

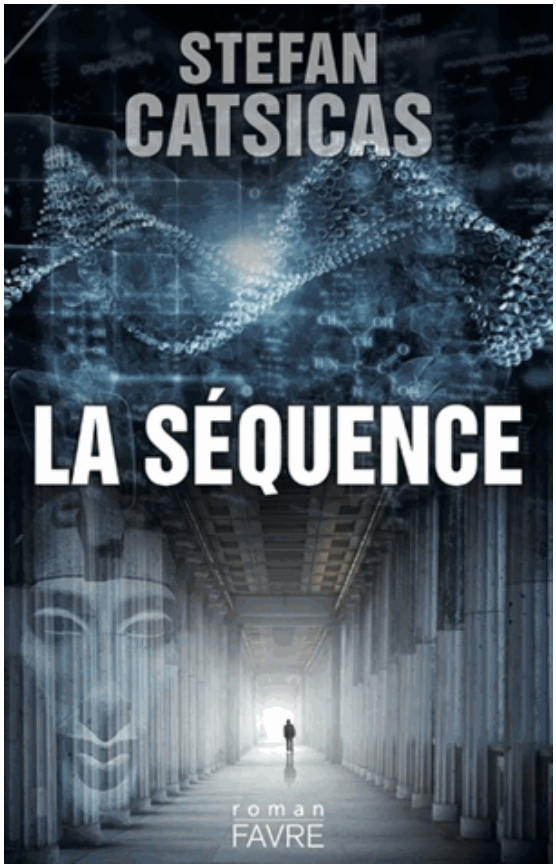
2019 ACTIVITIES
INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

PUBLICATION DU LIVRE "LA SÉQUENCE » UN THRILLER QUI PARLE DE GÉNÉTIQUE DE STEFAN CATSICAS

Stefan Catsicas, neurobiologiste, professeur à la faculté de médecine et à l'école polytechnique fédérale avant de devenir entrepreneur et dirigeant de multinationale, il a vécu en Europe, aux États-Unis et au Moyen-Orient. Thriller haletant, inspiré par le rôle de l'inné dans nos comportements et nos croyances, La Séquence est son premier roman.

Résumé: Deux amis, que l'amour d'une même femme a séparés, dominent la scène internationale de la génétique humaine. L'un, le Professeur Daniel Fox, est sur le point de recevoir le prix Nobel, mais l'analyse du génome du plus mystérieux des pharaons vient ébranler toutes ses théories. L'autre, Nelson Devennes, est un homme d'affaires charismatique, à la tête d'un véritable empire. Ensemble, ils avaient découvert un fragment d'ADN qui distingue l'humain de tout autre être vivant et qui aujourd'hui attire les convoitises : la Séquence. Son origine est inconnue et sa manipulation interdite, mais la fille de Daniel, la séduisante Elisa Fox, semble détenir la clé pour la maîtriser. La jeune femme devient alors la cible d'une organisation occulte qui opère à coups d'enlèvements et d'exécutions, entre les beaux quartiers de Manhattan, les laboratoires de San Diego et les sanctuaires des îles grecques. Un récit intense et passionnant, mêlant science, histoire, mythologie et spiritualité.

Les droits d'auteur sont versés au bénéfice de la BLACKSWAN Foundation pour la recherche sur les maladies rares et orphelines.



FINANCIAL REPORT 2019

ALBA

Lugano, 18th June 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 2019

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 2019.

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 2019 with a profit balance of Chf 40'318.62. The net asset of the Foundation, after capitalizing the annual result turn into a deficit asset balance of the amont Chf. 258'696.85.

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. Menmi Fava

Enclosures

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FINANCIAL REPORT
2019 BALANCE

BILANCIO patrimoniale al 31.12.2019

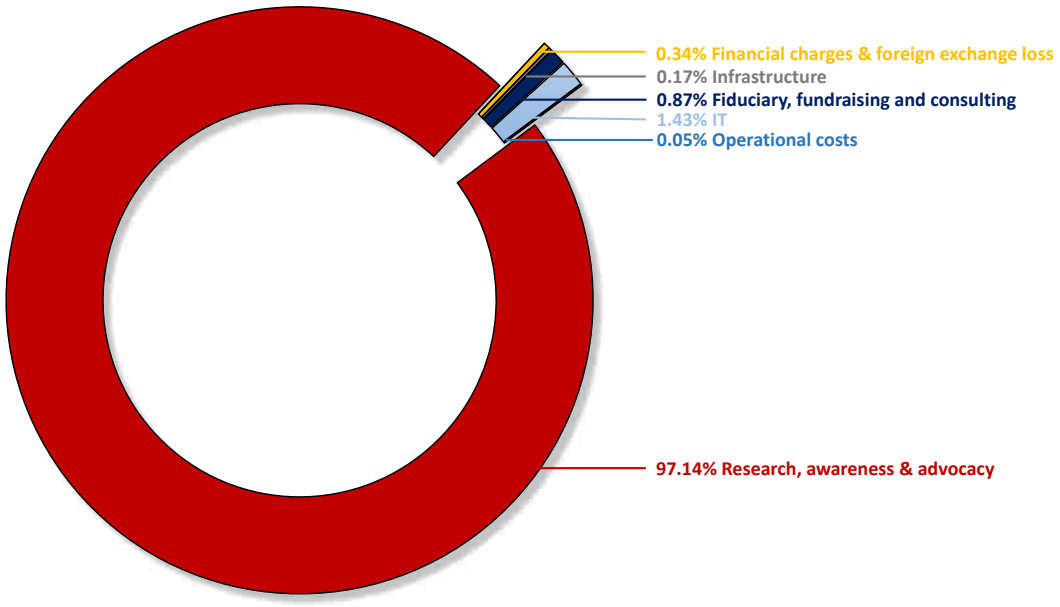
Conto	Descrizione	Dare (CHF)	Avere (CHF)	(2018 al 31.12.2018) Saldo prec (CHF)	Variazione	
	ATTIVI					
10	**Sostanza circolante**					
100	***Mezzi liquidi***					
1020	Banca EFG - 007 (Ex AA)	76'313.20		71'746.50 D	4'566.70	*6.4*
1021	Banca EFG - 015 (Ex AB)	1'259.67		1.17 A	-1'260.84	*999.9*
1022	Banca EFG - 031 (Ex MA)	86'573.89		83'204.83 D	3'369.06	*4.0*
1023	Banca EFG - 023 (Ex LA)	49'406.91		10'615.92 D	38'790.99	*365.4*
1024	Banca EFG - 058 Us$	14'621.09		9'159.56 D	5'461.53	*59.6*
1031	PayPal EUR	0.00		657.24 D	-657.24	*-100.0*
	Totale Mezzi liquidi	***228'174.76***	***0.00***	***175'382.88*** D	*52'791.88*	*30.1*
109	***Transitori***					
1090	Transitori attivi	8'172.77		5'505.15 D	2'667.62	*48.5*
1093	Transitorio Carta di credito		70.58	0.00 D	70.58	*100.0*
	Totale Transitori	***8'172.77***	***70.58***	***5'505.15*** D	*2'597.04*	*47.2*
	Totale Sostanza circolante	**236'347.53**	**70.58**	**180'888.03** D	55'388.92	*30.6*
11	**Sostanza fissa**					
1105	Mobilio e macchine ufficio	670.00		890.00 D	-220.00	*-24.7*
1106	Hardware e Software	3'180.00		5'300.00 D	-2'120.00	*-40.0*
1200	Attivazione Progetto RARevolution (2016-2019)	26'630.00		35'500.00 D	-8'870.00	*-25.0*
	Totale Sostanza fissa	**30'480.00**	**0.00**	**41'690.00** D	-11'210.00	*-26.9*
	Totale ATTIVI	**266'827.53**	**70.58**	**222'578.03** D	44'178.92	*19.8*
	PASSIVI					
20	**Capitale di terzi**					
200	***Debiti a breve termine***					
2000	Creditori		0.00	1'500.75 A	-1'500.75	*-100.0*
	Totale Debiti a breve termine	***0.00***	***0.00***	***1'500.75*** A	*-1'500.75*	*-100.0*
209	***Transitori***					
2090	Transitori passivi		6'500.00	3'500.00 A	3'000.00	*85.7*
2093	Transitorio stipendi		1'560.10	800.95 D	-2'361.05	*-294.8*
	Totale Transitori	***0.00***	***8'060.10***	***2'699.05*** A	*5'361.05*	*198.6*
	Totale Capitale di terzi	**0.00**	**8'060.10**	**4'199.80** A	3'860.30	*91.9*
21	**Capitale proprio**					
2150	Risultati riportati		218'378.23	195'774.54 A	22'603.69	*11.5*
2170	Risultato d'esercizio		40'318.62	22'603.69 A	17'714.93	*78.4*
	Totale Capitale proprio	**0.00**	**258'696.85**	**218'378.23** A	40'318.62	*18.5*
	Totale PASSIVI	**0.00**	**266'756.95**	**222'578.03** A	44'178.92	*19.8*
	Totale a pareggio	**266'827.53**	**266'827.53**			

FINANCIAL REPORT
2019 INCOME STATEMENT

CONTO economico dal 1.1.2019 al 31.12.2019

Conto	Descrizione	Dare (CHF)	Avere (CHF)	(2018 dal 1.1.2018 al 31.12.2018) Saldo prec (CHF)	Variazione	
	RICAVI D'ESERCIZIO					
60	**Ricavi da vendite**					
600	***Ricavi da vendite***					
6001	Registrazioni RE(ACT) congress		21'047.11	8'097.31 A	12'949.80	*159.9*
6002	Donazioni RE(ACT) community		0.00	7'186.02 A	-7'186.02	*-100.0*
6004	Donazioni libri ricette		0.00	1'410.00 A	-1'410.00	*-100.0*
6006	Donazioni PayPal		683.00	1'408.94 A	-725.94	*-51.5*
6008	Donazioni varie		128'915.78	968'972.11 A	-840'056.33	*-86.7*
6010	Donazioni progetto RAREvolution		134'381.34	62'221.87 A	72'159.47	*116.0*
6013	Sponsoring RE (ACT) Congress		134'104.51	2'556.58 A	131'547.93	*999.9*
6014	Rimborsi		144.30	215.82 A	-71.52	*-33.1*
	Totale Ricavi da vendite	***0.00***	***419'276.04***	***1'052'068.65*** A	*-632'792.61*	*-60.1*
	Totale Ricavi da vendite	**0.00**	**419'276.04**	**1'052'068.65** A	-632'792.61	*-60.1*
	Totale RICAVI D'ESERCIZIO	**0.00**	**419'276.04**	**1'052'068.65** A	-632'792.61	*-60.1*
	Risultato d'esercizio	***40'318.62***		***22'603.69*** D	17'714.93	*78.4*
	Totale a pareggio	**419'354.94**	**419'354.94**			

FINANCIAL REPORT
2019 EXPENSES OVERVIEW



NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2019

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.

FINANCIAL REPORT
2019 INCOME STATEMENT

CONTO economico dal 1.1.2019 al 31.12.2019

Conto	Descrizione	Dare (CHF)	Avere (CHF)	(2018 dal 1.1.2018 al 31.12.2018) Saldo prec (CHF)	Variazione	
	COSTI PER MATERIALE E MERCI					
	Totale COSTI PER MATERIALE E MERCI	**0.00**	**0.00**	**0.00** D	0.00	*100.0*
	COSTI D'ESERCIZIO					
40	**Costi del personale**					
4000	Stipendi e salari	0.00		21'600.00 D	-21'600.00	*-100.0*
4010	AVS/AI/IPG	0.00		3'296.25 D	-3'296.25	*-100.0*
4020	Assicurazione malattia	0.00		868.30 D	-868.30	*-100.0*
4030	Assicurazione infortuni	0.00		65.70 D	-65.70	*-100.0*
4040	Cassa pensione	0.00		5'691.90 D	-5'691.90	*-100.0*
4050	Imposte alla fonte	0.00		255.50 D	-255.50	*-100.0*
	Totale Costi del personale	**0.00**	**0.00**	**31'777.65** D	-31'777.65	*-100.0*
41	**ALTRI COSTI D'ESERCIZIO**					
4210	Interessi e spese diverse	24.99		74.49 D	-49.50	*-66.5*
4220	Spese bancarie	494.84		624.50 D	-129.66	*-20.8*
4250	Differenze di cambio	750.91		10'041.48 D	-9'290.57	*-92.5*
4260	Costi operazionali	0.00		15'370.56 D	-15'370.56	*-100.0*
4400	Ammortamenti	2'340.00		6'059.05 D	-3'719.05	*-61.4*
4401	Ammortamento progetti	8'870.00		17'750.00 D	-8'880.00	*-50.0*
4700	Materiale ufficio e stampati	644.30		3'720.38 D	-3'076.08	*-82.7*
4701	Promozione - stampati	320.00		204.00 D	116.00	*56.9*
4706	Spese brand, web domains	700.00		0.00 D	700.00	*100.0*
4720	Spese telefoniche/fax/postali	0.00		39.85 D	-39.85	*-100.0*
4760	Spese di rappresentanza	5'273.24		6'332.60 D	-1'059.36	*-16.7*
4770	Costi amministrativi e consulenze	0.00		34'708.10 D	-34'708.10	*-100.0*
4771	Tasse, Fiduciaria, membership	3'267.07		4'030.71 D	-763.64	*-18.9*
4775	Salari, Spese Sociali		78.90	0.00 D	78.90	*100.0*
4802	Sito web e webmaster	5'402.76		10'224.34 D	-4'821.58	*-47.2*
4830	RE(ACT) congress	113'060.07		78'846.50 D	34'213.57	*43.4*
4831	RE(ACT) Community	6'948.96		48'834.65 D	-41'885.69	*-85.8*
4832	RDI (Rare Disease International)	90'265.48		98'000.00 D	-7'734.52	*-7.9*
4890	Altri costi d'esercizio	0.00		36.62 A	-36.62	*100.0*
4891	Mix (carta di credito)	192.60		0.00 D	192.60	*100.0*
5000	Grants	140'481.10		662'862.72 D	-522'381.62	*-78.8*
	Totale Altri costi d'esercizio	**379'036.32**	**78.90**	**997'687.31** D	-618'729.89	*-62.0*
	Totale COSTI D'ESERCIZIO	**379'036.32**	**78.90**	**1'029'464.96** D	-650'507.54	*-63.2*

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

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www.blackswanfoundation.ch
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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

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1418 Vuarrens - Switzerland
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contact@blackswanfoundation.ch

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