Rapport Annuel

Annual Report

2015

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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WE AMPLIFY COLLECTIVE ACTION FOR RESEARCH ON RARE DISEASES

5YEARS

2010 - 2015

MESSAGE DU PRÉSIDENT

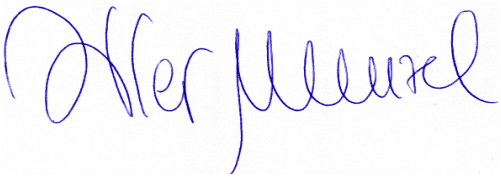
L'année 2015 a été celle qui fit entrer la Fondation BLACKSWAN dans une dimension encore plus internationale. En effet, en plus de la RE(ACT) Initiative, outil que nous avons créé spécialement pour les chercheurs et les patients, qui est composée du congrès international bisannuel RE(ACT) et de la plateforme de partage scientifique et de financement participatif, nous avons réfléchi, conceptualisé et créé le programme «#RAREvolution : Stand up for scientific research».

Le programme #RAREvolution ajoute une dimension de sensibilisation et de plaidoyer auprès du grand publique pour la cause des maladies rares.

Je suis convaincu qu'il faut obtenir un consensus international pour faire réagir les institutions capables d'augmenter les financements pour la recherche sur les maladies rares et orphelines et ainsi faire reconnaître les maladies rares comme un vrai problème de santé publique et une priorité de recherche. Pour rappel, il est estimé qu'environ un demi-milliard de personnes dans le monde sont touchées par une maladie rare, dont 75% sont des enfants.

C'est pour cela que 2015 a été une année charnière pour nous, tant au niveau développement stratégique que du positionnement, mais aussi dans la création et la consolidation de partenariats internationaux pour «hurler» d'une voix commune notre #RAREvolution pour une cause qui mérite d'être entendue et soutenue !

Olivier Menzel
Président et fondateur



"Nous remercions sincèrement tous ces généreux donateurs, mécènes, partenaires et bénévoles qui ont soutenu notre action"

MESSAGE FROM THE PRESIDENT

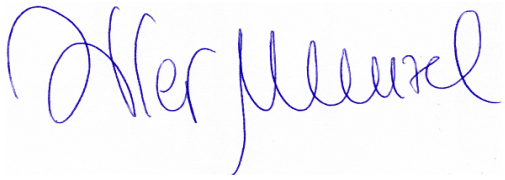
2015 marked a new start for the BLACKSWAN Foundation characterized by an even greater international dimension. In addition to the RE(ACT) Initiative focused on the creation of tools for researchers through the RE(ACT) Congress and the RE(ACT) Community, we have envisioned, conceptualized and built the program «#RAREvolution: Stand up for scientific research».

The #RAREvolution program includes the RE(ACT) Initiative that is especially conceived for researchers and patients and adds an awareness and advocacy campaign on rare diseases addressed to the general public.

I am convinced that we need to reach international consensus on the recognition of rare diseases as a global public health and research priority. Only in this way, institutions will increase funding on rare and orphan disease research. Let me remind you that approximately half a billion people are affected by rare diseases in the world and 75% of them are children.

This is why the year 2015 represents a turning point for us both for our strategic development and positioning in the international context. The creation and consolidation of international partners it is therefore capital to «shout» with a common voice our #RAREvolution in defense of a just cause that deserve to be heard!

Olivier Menzel
Chairman and Founder



"Our sincere gratitude goes to all those generous donors, sponsors, partners and volunteers who have supported our action"

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 ?

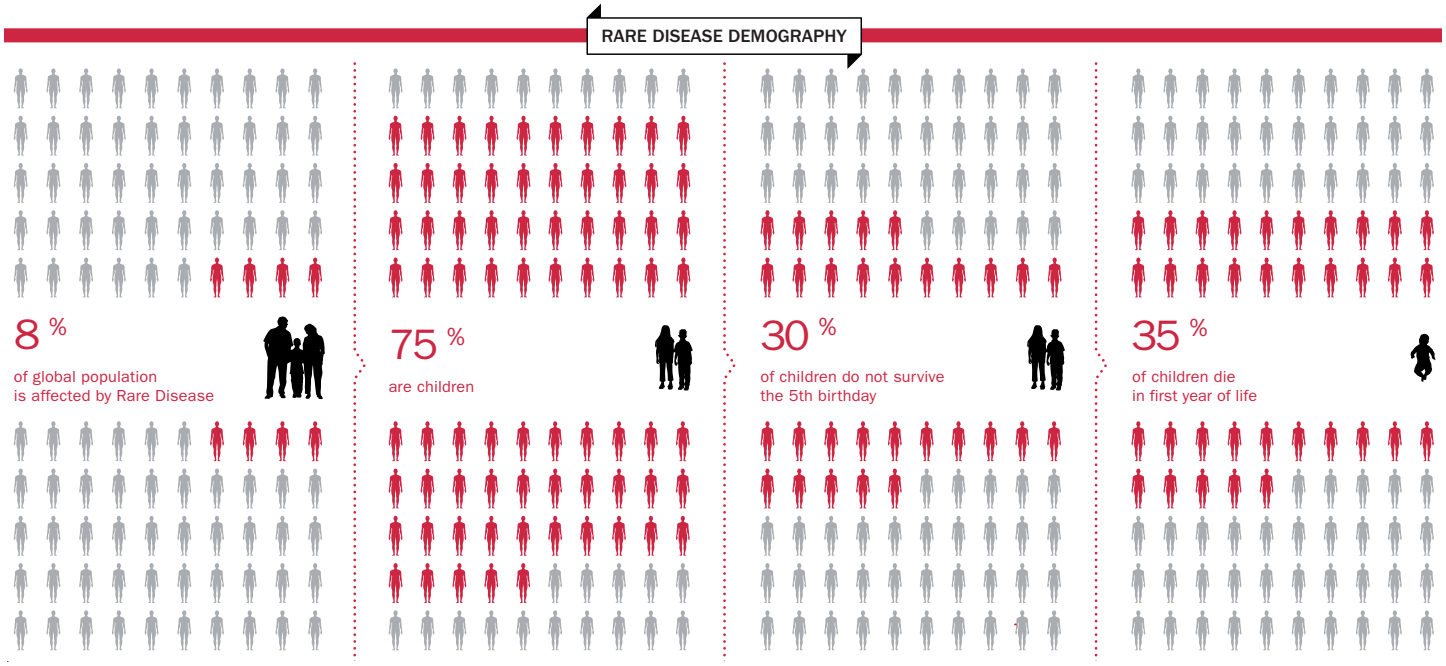
A disease or disorder is defined as rare in Europe and in Switzerland when it affects not more than 1 in every 2,000 persons. These conditions are generally chronic, progressive, debilitating and often life-threatening. In addition, these rare diseases present certain challenges for the development of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

> 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.

1 338 612 968 CHINA POPULATION

1 156 897 766 INDIA POPULATION

475 304 355 RARE DISEASE POPULATION

302 074 000 USA POPULATION

2015 ACTIVITIES
SUPPORT FOR SCIENTIFIC RESEARCH

In 2015, 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.

In 2015, the first research project: "Building a national biobank and registry of large and giant congenital melanocytic nevi" lead by Dr. Heather Etchevers at INSERM (Institut National de la Santé et la Recherche Médicale) Marseille, France collected through our crowdfunding platform, the amount of 36,030 Euro.

2015 ACTIVITIES
INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

PARTICIPATION IN THE LAUNCH OF RARE DISEASES INTERNATIONAL, THE GLOBAL VOICE FOR RARE DISEASE PATIENTS

Over 60 patient representatives from 30 countries gathered for the official launch and inaugural meeting of Rare Diseases International (RDI), held at the EURORDIS Membership Meeting 2015 in Madrid, and to adopt the principles of a joint declaration aimed at advocating for rare diseases to be an international public health priority.

RDI represents patients and families of all nationalities across all rare diseases and brings together umbrella patient organizations as well as international rare disease-specific federations from around the world.

The main objectives of RDI are:

> To promote rare diseases as an international public health and research priority by raising public awareness and influencing policy-making;

> To represent members and people living with a rare disease in international institutions such as the World Health Organization and the United Nations Economic and Social Council; and

> To enhance the capacities of members to improve the lives of those living with or affected by a rare disease through information exchange, networking, mutual support and joint actions.

BLACKSWAN Foundation is a member of Rare Diseases International.

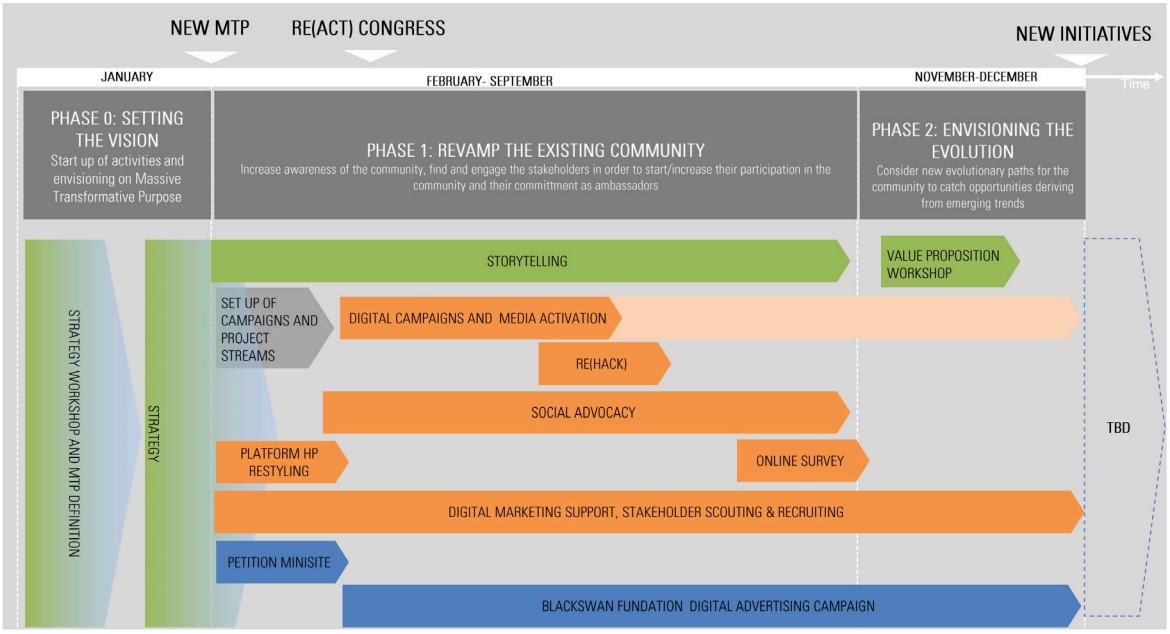
2015 ACTIVITIES
THINK TANK: #RAREVOLUTION

During the year 2015 the BLACKSWAN Foundation developed the #RAREvolution Program with the objective of facilitating the recognition of rare diseases as a public health and research priority and therefor improve public policies and attract more resources for the advance of therapies.
The #RAREvolution program combines the work and experience developed by the BLACKSWAN Foundation in the last years with new specific interventions.
#RAREvolution is structured on three main axes which run in parallel:

1. Awareness and Advocacy,
2. Support for Research, and
3. Strengthening of the already existing RE(ACT) Initiative

1. AWARENESS AND ADVOCACY (A&A) activities were defined to increase the understanding of rare diseases (RDs) among the public and encourage policy makers to recognize these conditions as a public health and research priority. Thanks to these actions, national governments should further engage in tackling the inequalities RD patients face every day and improve their access to prevention, diagnosis and treatment. A&A will also motivate the private sector to invest more in research for rare and orphan diseases.
The awareness activities focus on the implementation of an online communication campaign for rare diseases among the general public, decision makers, health professionals, researchers and academics.
The online communication campaign was outlined in cooperation with OpenKnowledge srl, a specialized international communication agency based in Milan, Sidney and London. The campaign will use the already existing BLACKSWAN Foundation's online platform RE(ACT) Community, as main communication channel.
The RE(ACT) Community will leverage on the power of its worldwide stakeholders (researchers, patients, backers) and the social networks of their own members.
The Community is a powerful story hub, a digital place where stakeholders meet together while sharing their projects, needs and goals. The platform will be transformed in a real content instrument, by using the news area of its home page as a logbook 2.0 where stakeholders will tell their best success stories and become the main Community's protagonists and storytellers.

The first year activities will be carried out throughout the entire 2016, according to the following time plan:



2015 ACTIVITIES
THINK TANK: #RAREVOLUTION

The first action for the campaign will be to envision a Massive Transformative Purpose (MTP), which is a short impactful statement that describes what the organization aspires to accomplish rather than what it does. The MTP will be created through a dedicated workshop with all relevant stakeholders (BLACKSWAN Foundation, researchers, medical start-ups, patients and families). The workshop will be managed through co-design thinking methodologies. The MTP will be the building block on which all the activities towards the stakeholders will be based on, as it will guide the choice of channels and contents for the communication activities, the digital storytelling that will be developed, the mood delivered through the community redesign.

Throughout the entire project period, the communication agency will scout online conversations and social interactions, in order to continuously detect stakeholders to get in touch with and engage as project candidates, advocates, storytellers and backers. A list of international relevant people to engage and keep a conversation with will be constantly updated and used for the advocacy and engagement activities.

The #RAREvolution advocacy activities are based on collaboration and mutual empowerment amongst rare diseases organizations. During the grant phase, BSF received official support for the implementation of the Program from a series of important partners that will help the Foundation in its advocacy task at international level. In this context, the Foundation's role will be to support and empower its international partners (patient organizations) in their communication and advocacy work.

2. SUPPORT FOR RESEARCH

As part of the #RAREvolution Program, BSF developed a grant strategy to bring fast and concrete results in diagnostics and treatments innovation for rare diseases. This action has also the objective to prove to governments that investing in research and making rare diseases a global health and research priority is also cost effective. In fact, misdiagnosis and delays in diagnosis of rare disease patients often lead to increased cost burdens on healthcare systems due to inadequate treatments. Moreover, it has been proved that disease-specific projects can help discovering new therapies for more common diseases and benefit a larger population.

The support for research is studied to be rolled through two types of grants: a) Quick Impact Interventions (QIs) and b) #RAREvolution Grants (RRG).

a) Quick Impact Interventions (QIs) can shorten the timespan needed to develop treatments and generate tangible benefits for patients at reduced cost. Examples of QIs include drug repurposing, patient recruitment and patient registers.
b) #RAREvolution International Grants (RRG) will fund specific research projects with the aim to improve the treatment of rare genetic diseases. Grants are aimed at researchers developing and implementing innovative approaches or technologies to address currently unresolved rare genetic disease needs.

An independent scientific committee allocates the grants on the basis of pre-approved criteria and processes. Research results are published in scientific journals, which will be embedded in the #RAREvolution communication campaign as well as being presented at the RE(ACT) Congress, the International Congress on Research of Rare and Orphan Diseases.

3. STRENGTHENING THE RE(ACT) INITIATIVE

The RE(ACT) Initiative has been developed by the BLACKSWAN Foundation in 2012 to provide to researchers working on rare diseases tools that improve coordination among laboratories (particularly important to avoid duplication of studies) and increase knowledge sharing (because of the limited knowledge available on rare diseases). The Initiative comprises the RE(ACT) Congress and the online platform RE(ACT) Community.

2015 ACTIVITIES
THINK TANK: #RAREVOLUTION

The RE(ACT) Congress is the first international scientific congress organized to discuss research on rare and orphan diseases. The event is an international reference point for rare disease experts and brings together, every two years, world leading researchers and young scientists to present state of the art research on rare diseases, discuss results and exchange ideas. The unique feature of the RE(ACT) Congress is that specialists from different fields of research come together to address rare diseases and treatments across the boundaries of their own disciplines.

Under the #RAREvolution Program, the RE(ACT) Community was restructured in order to attract more visitors and increase coordination on research and interactions of researchers and patients. The platform, which helps researchers to connect with other researchers and promotes scientific information exchange among researchers and patients is also a crowdfunding platform for scientific projects.
In order to revamp the Community, the #RAREvolution

Program conceived two different and complementary ways:

- Set-up and daily optimization of a Facebook and Google campaign, directly linking to the platform's core web pages.
- Discovery, activation and interactions with a pool of reputed national/international magazines and blogs, in order to publish articles and SEO-relevant contents about the RE(ACT) Community and its fresh news.

The restructure envisages also some layout re-design activities to be carried out before the RE(ACT) Congress in March 2016. In particular, modifying the home page of the Community as follows:

1. Integrate banners into a slider in the main area, coherently with eye tracking studies showing that consumers have "banner blindness".
2. Provide a slider on the left side of the page to promote the project's initiatives, news and events, while the main part of the area should contain a strong headline to present its MTP.
3. Modify the graphics of the 'donate' button and place it on the header, since it will show up on any monitor to users when they land on, no matter the screen size or resolution
4. Add a 'featured on' space, to show logos and links of the main digital media talking about the project.
5. Improve the overall look&feel of the infographic, to engage the site's visitors by giving sense of urgency while moving to learn more.

The whole #RAREvolution Program is conceived to be implemented in cooperation with other rare disease organizations. The BLACKSWAN Foundation already collaborates with national and international patient organizations, academic institutions, research consortia and centers of expertise. All these institutions are key players in the field of rare diseases and express their interest to be part of #RAREvolution.

Commitment to take part to the implementation of the #RAREvolution Program has already been made by the following organizations: Eurordis (European alliance for rare disease patients), Proraris (Swiss alliance for rare disease patients), E-Rare (European Commission consortium of national funding bodies for research on rare diseases), RDI (Rare Diseases International), NGO Committee for rare diseases at the United Nations.

This program was developed thanks to the financial contribution of Philip Morris International.

2015 ACTIVITIES
AN EVENING ON THE NEPTUNE BOAT

In July 2015, the Foundation in collaboration with its volunteers (BLACKSWAN Events Geneva) organized a social fundraising event in Geneva on the historical sailing boat “the Neptune”. During this convivial moment, the president of the BLACKSWAN Foundation gave a speech to thank the participants and to increase awareness on rare and orphan diseases.

FINANCIAL REPORT 2015

ALBA

Lugano, 23rd November 2016

To the
General meeting of the
Blackswan Foundation
Via Cantonale 26
6948 Porza

REPORT OF THE STATUTORY AUDITORS
YEAR 2015

As statutory auditor, we have audited the accounting records and the financial statements (balance sheet, income statement and notes) of Blackswan Foundation for the year ending 31 December 2015.

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 examinated 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 close the accounting year 2015 with a deficit balance of Chf 5'999.36. The net asset of the Foundation, after capitalizing the annual result turn into a postiv asset balance of the amont Chf. 81'436.11.

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

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info@albadvisors.ch - www.albadvisors.ch - No. IVA: CHE-108.642.160

FINANCIAL REPORT
2015 BALANCE

BLACKSWAN FONDAZIONE
Via Cantonale 26
6948 Porza

Stampato il 24.11.2016/09:35:05
Contabilità 2015 dal 1.1.2015 al 31.12.2015

BILANCIO patrimoniale al 31.12.2015

Conto	Descrizione	Dare (CHF)	Avere (CHF)	(2014 al 31.12.2014) Saldo prec (CHF)	Variazione	
	ATTIVI					
10	**Sostanza circolante**					
100	***Mezzi liquidi***					
1020	Banca BSI c/ 414 AA	6'517.25		99'828.63 D	-93'311.38	*-93.5*
1021	Banca BSI c/ 414 AB	796.07		60.40 D	735.67	*999.9*
1022	Banca BSI c/ 414 MA	8.01		0.00 D	8.01	*100.0*
1023	Banca BSI c/ 414 LA	9'042.90		0.00 D	9'042.90	*100.0*
1030	PayPal	240.40		51.63 D	188.77	*365.6*
1031	PayPal EUR	294.68		585.63 D	-290.95	*-49.7*
	Totale Mezzi liquidi	***16'899.31***	***0.00***	***100'526.29*** D	*-83'626.98*	*-83.2*
109	***Transitori***					
1090	Transitori attivi	4'251.35		0.00 D	4'251.35	*100.0*
	Totale Transitori	***4'251.35***	***0.00***	***0.00*** D	*4'251.35*	*100.0*
	Totale Sostanza circolante	**21'150.66**	**0.00**	**100'526.29** D	-79'375.63	*-79.0*
11	**Sostanza fissa**					
1105	Mobilio e macchine ufficio	4'515.00		6'020.00 D	-1'505.00	*-25.0*
1106	Hardware e Software	2'590.00		910.00 D	1'680.00	*184.6*
1200	Attivazione Progetto RARevolution (2016-2019)	71'000.00		0.00 D	71'000.00	*100.0*
	Totale Sostanza fissa	**78'105.00**	**0.00**	**6'930.00** D	71'175.00	*999.9*
	Totale ATTIVI	**99'255.66**	**0.00**	**107'456.29** D	-8'200.63	*-7.6*
	PASSIVI					
20	**Capitale di terzi**					
200	***Debiti a breve termine***					
2000	Creditori		8'061.95	12'020.82 A	-3'958.87	*-32.9*
	Totale Debiti a breve termine	***0.00***	***8'061.95***	***12'020.82*** A	*-3'958.87*	*-32.9*
209	***Transitori***					
2090	Transitori passivi		4'000.00	2'000.00 A	2'000.00	*100.0*
2093	Transitorio stipendi	242.40		0.00 D	242.40	*100.0*
2095	Accantonamento imposte		6'000.00	6'000.00 A	0.00	*0.0*
	Totale Transitori	***242.40***	***10'000.00***	***8'000.00*** A	*1'757.60*	*22.0*
	Totale Capitale di terzi	**242.40**	**18'061.95**	**20'020.82** A	-2'201.27	*-11.0*
21	**Capitale proprio**					
2150	Risultati riportati		87'435.47	85'049.65 A	2'385.82	*2.8*
2170	Risultato d'esercizio	5'999.36		2'385.82 A	-8'385.18	*-351.5*
	Totale Capitale proprio	**5'999.36**	**87'435.47**	**87'435.47** A	-5'999.36	*-6.9*
	Totale PASSIVI	**6'241.76**	**105'497.42**	**107'456.29** A	-8'200.63	*-7.6*
	Totale a pareggio	**105'497.42**	**105'497.42**			

FINANCIAL REPORT
2015 INCOME STATEMENT

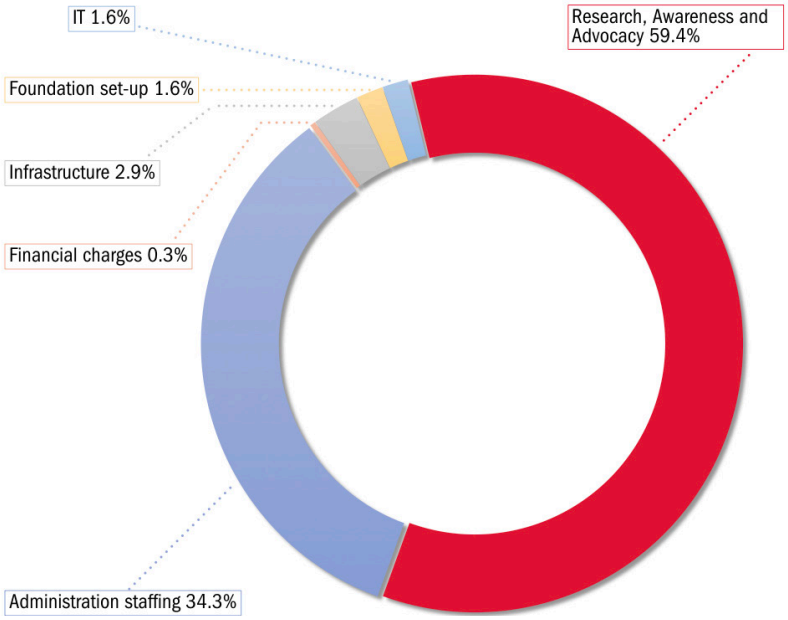
BLACKSWAN FONDAZIONE
Via Cantonale 26
6948 Porza

Stampato il 24.11.2016/09:35:39
Contabilità 2015 dal 1.1.2015 al 31.12.2015

CONTO economico dal 1.1.2015 al 31.12.2015

Conto	Descrizione	Dare (CHF)	Avere (CHF)	(2014 dal 1.1.2014 al 31.12.2014) 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	67'200.00		0.00 D	67'200.00	*100.0*
4010	AVS/AI/IPG	8'126.00		0.00 D	8'126.00	*100.0*
4020	Assicurazione malattia	786.10		0.00 D	786.10	*100.0*
4030	Assicurazione infortuni	88.40		0.00 D	88.40	*100.0*
4040	Cassa pensione	4'840.20		0.00 D	4'840.20	*100.0*
4050	Imposte alla fonte		25.95	0.00 D	25.95	*100.0*
	Totale Costi del personale	**81'040.70**	**25.95**	**0.00** D	81'014.75	*100.0*
41	**ALTRI COSTI D'ESERCIZIO**					
4210	Interessi e spese diverse	43.87		811.03 D	-767.16	*-94.6*
4220	Spese bancarie	660.93		399.00 D	261.93	*65.6*
4250	Differenze di cambio	95.01		674.30 D	-579.29	*-85.9*
4400	Ammortamenti	3'232.70		2'970.00 D	262.70	*8.8*
4401	Ammortamento progetti	17'668.89		0.00 D	17'668.89	*100.0*
4700	Materiale ufficio e stampati	6'000.00		507.25 D	5'492.75	*999.9*
4701	Promozione - stampati	318.60		0.00 D	318.60	*100.0*
4703	Spese Gala	1'300.00		1'100.00 D	200.00	*18.2*
4704	Promozione e marketing	1'944.56		2'149.08 D	-204.52	*-9.5*
4706	Spese brand, web domains	0.00		100.00 D	-100.00	*-100.0*
4720	Spese telefoniche/fax/postali	647.30		7'344.00 D	-6'696.70	*-91.2*
4730	Spese TforT	0.50		4'676.82 D	-4'676.32	*-100.0*
4760	Spese di rappresentanza	8'767.17		5'668.51 D	3'098.66	*54.7*
4770	Costi amministrativi e consulenze	0.00		5'400.00 D	-5'400.00	*-100.0*
4771	Tasse, Fiduciaria, membership	3'832.00		2'376.00 D	1'456.00	*61.3*
4802	Sito web e webmaster	3'676.16		754.19 D	2'921.97	*387.4*
4830	RE(ACT) congress	66'014.26		125'280.15 D	-59'265.89	*-47.3*
4831	RE(ACT) Community	20'342.37		0.00 D	20'342.37	*100.0*
4832	RDI (Rare Disease International)	24'000.00		0.00 D	24'000.00	*100.0*
4890	Altri costi d'esercizio	100.00		0.00 D	100.00	*100.0*
	Totale Altri costi d'esercizio	**158'644.32**	**0.00**	**160'210.33** D	-1'566.01	*-1.0*
	Totale COSTI D'ESERCIZIO	**239'685.02**	**25.95**	**160'210.33** D	79'448.74	*49.6*

FINANCIAL REPORT
2015 EXPENSES OVERVIEW



NOTES TO FINANCIAL STATEMENTS FOR THE YEAR ENDED 31 DECEMBER 2015

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 an unrestricted contribution from Philip Morris International for the specific purpose to support the "administration staffing" 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
2015 INCOME STATEMENT

BLACKSWAN FONDAZIONE
Via Cantonale 26
6948 Porza

Stampato il 24.11.2016/09:35:39
Contabilità 2015 dal 1.1.2015 al 31.12.2015

CONTO economico dal 1.1.2015 al 31.12.2015

Conto	Descrizione	Dare (CHF)	Avere (CHF)	(2014 dal 1.1.2014 al 31.12.2014) Saldo prec (CHF)		Variazione	
	RICAVI D'ESERCIZIO						
60	**Ricavi da vendite**						
600	***Ricavi da vendite***						
6001	Registrazioni RE(ACT) congress		14'928.58	0.00	A	14'928.58	*100.0*
6002	Donazioni RE(ACT) congress		81'494.76	0.00	A	81'494.76	*100.0*
6003	Donazioni TforT		7'219.60	0.00	A	7'219.60	*100.0*
6004	Donazioni libri ricette		410.00	410.00	A	0.00	*0.0*
6006	Donazioni PayPal		1'135.97	20'319.41	A	-19'183.44	*-94.4*
6007	Grants		0.00	18'320.32	D	-18'320.32	*100.0*
6008	Donazioni varie		31'212.80	38'880.60	A	-7'667.80	*-19.7*
6009	Donazioni Libro Rare Disease		32.00	166.46	A	-134.46	*-80.8*
6010	Donazioni progetto RAREvolution		93'310.00	98'380.00	A	-5'070.00	*-5.2*
6011	Donazioni Particolari (Azioni esterne, lasciti, decessi)	0.00		20'600.00	A	-20'600.00	*100.0*
6012	Donazioni Gala/Eventi		3'900.00	2'160.00	A	1'740.00	*80.6*
6050	Interessi attivi		16.00	0.00	A	16.00	*100.0*
	Totale Ricavi da vendite	***0.00***	***233'659.71***	***162'596.15***	A	*71'063.56*	*43.7*
	Totale Ricavi da vendite	**0.00**	**233'659.71**	**162'596.15**	A	71'063.56	*43.7*
	Totale RICAVI D'ESERCIZIO	**0.00**	**233'659.71**	**162'596.15**	A	71'063.56	*43.7*
	Risultato d'esercizio		***5'999.36***	***2'385.82***	D	-8'385.18	*-351.5*
	Totale a pareggio	**239'685.02**	**239'685.02**				

BLACKSWAN FOUNDATION AFFILIATIONS & PARTNERS

- ProRaris - Swiss rare disease alliance
- EURORDIS - European alliance of patient organizations
- E-RARE - European Consortium of national funding bodies for research on rare diseases
- RDI - Rare Disease International - The the global alliance of people living with a rare disease of all nationalities across all rare diseases

NEW PARTNERSHIP

Rare Disease International (RDI) brings together national and regional rare disease patient organizations from around the world as well as international rare disease-specific federations to create the global alliance of rare disease patients and families.

RDI's mission is to be a strong common voice on behalf of all people living with a rare disease around the world, to advocate for rare diseases as an international public health priority and to represent its members and enhance their capacities.

The BLACKSWAN Foundation welcomes this new important partnership and is honored to work with RDI.

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(i.e. for an immediate donation of 100 CHF, send BS 100 to 339).

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