

# Annual Report 2014

**BLACKSWAN<sup>®</sup>**  
**FOUNDATION**

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

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# MESSAGE FROM THE PRESIDENT

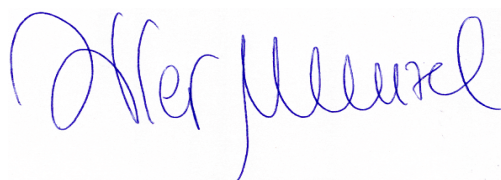
Despite the high number of people affected by rare and orphan diseases and an increasing interest from the industry, financial means to support research are still limited. Clinical research is highly fragmented, which brings to an even more inefficient use of resources. Increasing international cooperation and the active participation of patients to clinical trials are key to success in the rare disease field.

Since its inception in 2010, the Foundation has financially supported research projects, but the scarce availability of funds, peculiar to this field, was sometimes problematic. Then in 2012 we had the idea to promote a more sustainable use of resources and we decided to create new tools to help the scientific community in building synergies.

In March 2014, the BLACKSWAN Foundation inaugurated the second edition of the RE(ACT) Congress. Scientific meetings are an excellent opportunity for researchers working in a similar field to come together, learn about recent advances in the area, foster new collaborations and inspire new ideas. What is new about the RE(ACT) Congress is its interdisciplinary approach and the active participation of patients to its sessions. During the opening ceremony of the Congress, the BLACKSWAN Foundation officially launched the RE(ACT) Community. This online platform has a huge potential to connect researchers working in the field of rare diseases, it helps them to cross borders and meet online. It offers the possibility to find new collaborations, to share knowledge and at the same time to learn from others so to accelerate treatments' discovery. What is also interesting about the Community is the possibility to start a crowdfunding campaign and raise funds to set up a research project.

We believe that the RE(ACT) Congress and Community are effective ways to enhance international cooperation in the field of rare diseases, for this reason we will continue to work hard to improve them. On the other hand, the BLACKSWAN Foundation is also focusing its efforts in creating new opportunities to raise awareness and advocate to the benefit of rare disease patients. The public understanding of rare disease issues and a stronger political implication at international level can make the difference for millions of individuals.

Olivier Menzel  
President and Founder



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

# ABOUT RARE AND ORPHAN DISEASES

A disease is considered rare by its incidence when it affects less than 1 in 2,000 citizens<sup>1</sup>. Despite the rarity of each rare disease taken on its own, it is surprising to discover that all together about 500 million people are affected by these conditions in the world. There are an estimated 8,000 rare diseases affecting 8% of the global population – it is estimated that 75% of affected people are children and very sadly 30% of them will die before their fifth birthday.

Rare diseases are often associated with severe disabilities and premature death; they are chronic, progressive, degenerative and disabling. People living with a rare disease face many common challenges, such as delayed or inaccurate diagnosis, difficulty accessing healthcare and lack of knowledge or access to medical expertise.

Because of the low individual prevalence, these diseases do not represent a public health priority for governments and little research is performed. The market is so narrow for each disease that the pharmaceutical industry is reticent to invest in research to develop new treatments.

## CHALLENGES AND OPPORTUNITIES OF RESEARCH ON RARE DISEASES

Research in rare and orphan diseases faces two major hurdles: epidemiology (low number of subjects/patients for each disease) and financial constraints (these diseases are considered economically uninteresting for the industry).

Research on rare and orphan diseases is important because can serve as a model to understand more common diseases and consequently help a larger population. To be optimal, research on rare diseases should be developed in collaboration with specialists from around the world, thereby including the greatest number of patients and allow for an exchange of multidisciplinary expertise and best practices.

To motivate the industry to enter this small market, there has been legislation in the US (Orphan Drug Act in 1983), the EU (EU Regulation No. 141/2000) and other countries in the world, which provides regulatory and financial incentives aimed at stimulating investment in ‘orphan drugs’ to treat rare diseases. The incentives offer the opportunity to develop market “niche”, particularly interesting for small and medium enterprises.

While there have been significant advances in the field of rare diseases, effective therapies are still not available to more than 95% of the patients suffering from these diseases. In addition, while orphan drug designations have increased, there continues to be only a consistently small number of annual approvals for orphan drugs. So while there have been successes in the development of treatments for diseases, much remains to be achieved to the benefit of patients suffering from rare diseases.

<sup>1</sup>In Europe a disease is defined rare when it affects less than 1 in 2000; in the United States when it affects less than 200,000 Americans.

# THE FOUNDATION

## THE FOUNDATION IN BRIEF

The BLACKSWAN Foundation is a not-for-profit organization based in Switzerland and created in 2010 to contribute to the development of research on rare and orphan diseases worldwide. Its principal mission is to encourage therapeutic research and to promote information campaigns for a better public understanding of rare conditions.

The Foundation is a unique organisation supporting rare disease research as a whole. This approach takes into account the complexity and hurdles of rare disease research, helps in finding new solutions that can assist a larger variety of projects and allows the Foundation to have a greater influence on the public opinion.

Cooperation with other rare disease organizations is of utmost importance for the Foundation, which collaborates with national and international patient organizations, academic institutions, research consortia, centres of expertise. All of these institutions are key players in the field of rare diseases. The BLACKSWAN Foundation is a member of EURORDIS, the European alliance and ProRaris, the Swiss alliance of patient organisations.

The BLACKSWAN Foundation is represented by its multi talented Board of Trustee and advised by its Scientific Advisory Board (SAB). The Board of Directors is comprised of experts from a range of disciplines including finance, law and the health sciences. The SAB is composed by fourteen world leader researchers coming from Australia, Belgium, France, Italy and the US.

The Foundation is officially inscribed in the Swiss commercial register; it is supervised by the competent authority at the Swiss Federal Department of Home Affairs (FDHA) and recognized as a public utility foundation.



# 2014 ACTIVITIES SUPPORT FOR SCIENTIFIC RESEARCH

In 2014, BLACKSWAN Foundation efforts to support scientific research focused on two main activities: the organization of the second edition of the RE(ACT) Congress and on the public launch of an online platform, the RE(ACT) Community. Both initiatives were conceived to help researchers working in the field of rare and orphan diseases to create new collaborations, share knowledge and promote their scientific projects.

## **SECOND EDITION OF THE RE(ACT) CONGRESS**

From 5th to 8th March 2014, more than 300 experts from around the world attended the second edition of the RE(ACT) Congress at the Gehry building on the Novartis Campus in Basel, Switzerland. Participants discussed about the most cutting-edge research into rare diseases and the development of orphan drugs.

Rare diseases have long been seen as the orphan child of medicine: low levels of interest, little research and few active substances. The RE(ACT) Congress proved that the orphan is growing up. Research, industry and policymakers start to recognize the significance of these diseases and the challenges facing patients. In Switzerland, as in other countries, there has been a huge transformation over the past ten years.

The opening ceremony of the Congress started with the speech of Dr Jörg Reinhardt, Chairman of the

Board of Directors of Novartis, who stressed how important these diseases are and referred to over 40 research projects currently underway in his company. His talk was followed by presentations of David Lee, Head of the Autoimmunity, Transplant and Dermatology Translational Medicine Research Group at Novartis; of Yann Le Cam, CEO of EURORDIS and Stephen Groft, the former Head of the NIH's Office for Rare Disease Research with moderation performed by Susan Gasser, CEO of the Friedrich Miescher Institute.

Each speaker emphasized the progress that has been made and how the number of researchers, companies and patient organizations that are involved with rare diseases is growing rapidly. Regulatory laws have encouraged companies to develop treatments for rare diseases, research frameworks in the US and EU have been strengthened, patient organizations and lobby organizations such as EURORDIS and NORD are more active, and the financial community dedicated more investment capitals to rare diseases research.

The interventions during the Congress also stressed the importance of setting up international collaborations on research and good partnerships with patients and their families, public authorities, universities and industry in order to achieve excellent research results. «This is why congresses such as RE(ACT) are extremely important as they enable new



# 2014 ACTIVITIES SUPPORT FOR SCIENTIFIC RESEARCH

networks to be established», said Yann Le Cam, CEO of Eurordis, the European patient organization alliance.

from the scientific community in university and industry

## CONGRES GOALS

- Promote awareness on rare and orphan disease research among the general public, industry and policy makers
- Bring together researchers and their knowledge
- Help the understanding of other more common diseases
- Encourage clear insights positions identifiable

## MAIN TOPICS

- Stem cell and cell therapy approaches
- Mapping diseases and genome instabilities
- Pathophysiology and diagnostics
- Bringing treatments to the clinic
- Degenerative disorders
- Research and Patients



*“The RE(ACT) Congress program was excellent and I learned a lot. I would be honored to speak at the next RE(ACT) meeting”. Prof. Marshall L. Summar, MD, Chief Genetics and Metabolism Children’s National Medical Center, Washington D.C.*

*“It was my privilege to be invited to address your excellent conference. You have to be praised, together with all who contribute, for your outstanding efforts and achievements”. Yann Le Cam, CEO EURORDIS*

*“I hope you felt all of the time and effort you devote to this Congress was and will continue to be worthwhile and rewarding with years of returns resulting from the discussions of the time spent together.” Prof. Steve Groft, former NIH Director*



# 2014 ACTIVITIES SUPPORT FOR SCIENTIFIC RESEARCH

## THE ONLINE RE(ACT) COMMUNITY

The online platform RE(ACT) Community was officially launched on the 5th of March 2014 during the opening ceremony of the RE(ACT) Congress. This is a web-based network aimed at exchanging knowledge, bringing experts together and raise funds for new 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.

The RE(ACT) Community count a database of approximately 7'000 rare diseases. Each disease dossier includes the name of the disease, a description of the disease and its symptoms, possible research projects ready for funding and prospective amount of donations received for a project, information on scientific publications and research, patients' experiences, names of researchers and patients following the disease.

The Community is managed by a Secretariat, which deals with the overall coordination and administration of the Community and a Scientific Advisory Board (SAB) that assures internal control of the scientific contents exchanged in the Community. The SAB is also responsible to evaluate the eligibility of a project to crowdfunding in order to guarantee high standards of quality to the public.

In less than a year, 400 users registered on the platform and one project was declared eligible for crowdfunding and reached its funding target.

## THE ONLINE RE(ACT) COMMUNITY

In July 2014, the Scientific Advisory Board of the RE(ACT) Community declared eligible for crowdfunding a first research project: "Building a national biobank





# 2014 ACTIVITIES

## SUPPORT FOR SCIENTIFIC RESEARCH

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.

The biobank will enable the development of cellular and xenograft models that will allow further exploration of the specific aspects of large and giant congenital melanocytic nevi (CMN) but also more general principles underlying the mechanistic links between developmental anomalies, cellular senescence and cancer.

The project, seeking funding to employ a dedicated clinical research technician for two years, to coordinate data entry and sample processing, successfully reached the first milestone and collected 15'000 euro on the 31st of October 2014. Other funding targets are planned for the year 2015 to go over all records proposed by French-speaking patient associations in order to boost recruitment for both the national and international registries of this rare malformation. Partial funding will also be applied to the culture reagents necessary to develop and begin to study the iPS cell lines.

*“The RE(ACT) Community is the perfect tool for a researcher seeking for international collaboration in order to fulfil the patients’ expectations. Moreover it could be a source of funding and knowledge, great idea!”*  
*Neurofibromatosis researcher, Italy*

*«My feeling is that RE(ACT) is working positively to break down the barriers between researchers and patients and that is very welcome to us. I hope this can be carried through by empowering us to make more of a contribution.”*  
*MdDS patient, UK*

*“I’m so glad about the outside supporter.... but thank you to YOU first, for being a very early and very inside supporter. Had you not come up with this idea, I wouldn’t have undertaken this particular venture.”*  
*Congenital melanocytic nevus (CMN) researcher, France*

# INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS

In 2014 the BLACKSWAN Foundation participated to several local events in order to raise funds and increase awareness on rare and orphan diseases. These actions amplified the understanding of rare conditions in the local community and contributed to finance the foundation's projects.

## KIWANIS CLUB EVENT

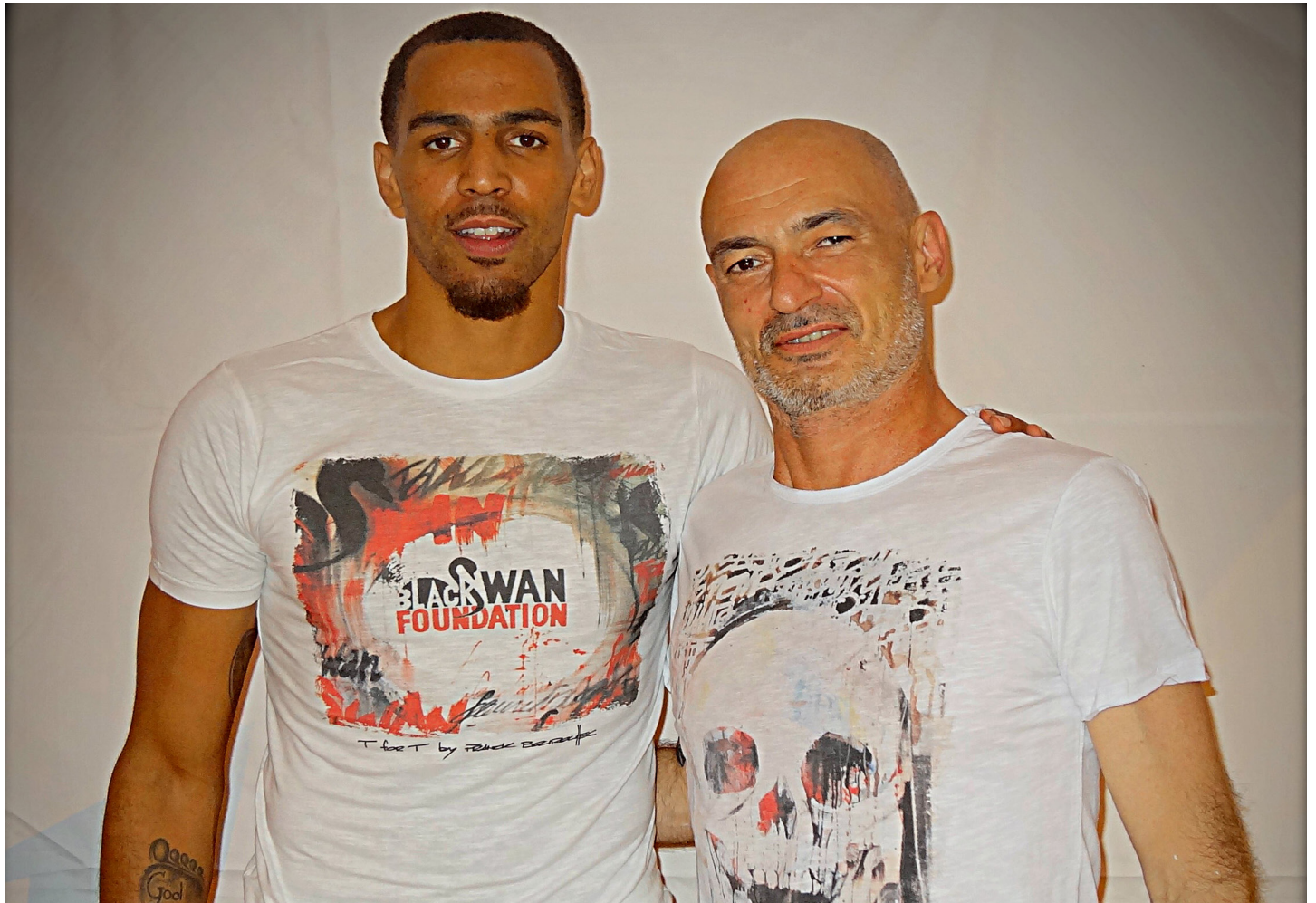
During a country festival in Montricher, Switzerland with over 500 participants the BLACKSWAN Foundation was awarded with a check of CHF 12,000 by Mr. José Redard, former President of the Kiwanis Cossonay. The Kiwanis Cossonay Club mission is to support people in need, his action is focused on children and in 2013 and 2014 the club dedicated a special attention to rare and orphan diseases.

## A RARE MOMENT FOR RARE DISEASES

In June 2014, the Foundation in collaboration with its volunteers organized a social 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 their awareness on rare and orphan diseases.



# INITIATIVES TO INCREASE AWARENESS AND COLLECT FUNDS



Thabo Sefolosha (professional basketball player, Atlanta Hawks, NBA) and Franck Bouroullec (painter performer) wearing T for T t-shirts. Vevey, June 2014.

## **T FOR T (T-SHIRTS FOR THERAPY)**

T for T stands for T-shirt for Therapy, a campaign of the BLACKSWAN Foundation. The aim of “T for T” is to increase awareness on rare and orphan diseases and to collect funds to support the discovery and development of new therapies for these conditions.

The painter-performer Franck Bouroullec is the artistic director of the campaign. He decided to put his talent at the service of the rare diseases cause. Franck portraits of celebrities have gained growing recognition and are renowned in all continents. The portraits of past and present celebrities together with a

reinterpretation of the BLACKSWAN Foundation’s logo are available on a limited series of T-shirts as part of the campaign T for T at the online shop: <http://tfortherapy.org>.

In 2014, the Swiss branch of Alexion, a pharmaceutical company specialized in drug development for rare conditions, offered a “T for T” t-shirt to its employee. During the traditional Christmas employees dinner More than a hundred Alexion’s employees received a BLACKSWAN Foundation’s t-shirt.



# FINANCIAL REPORT 2014



Lugano, 12 giugno 2015

Spettabile  
Assemblea dei soci della  
**Blackswan Fondazione**  
Via Cantonale 26  
6948 Porza

## RAPPORTO DI REVISIONE ESERCIZIO 2014

Nella nostra qualità di Ufficio di controllo abbiamo verificato l'esattezza dei conti della vostra Fondazione, per l'esercizio chiuso al **31 dicembre 2014**.

Il Consiglio di Fondazione è responsabile dell'allestimento del conto annuale, mentre il nostro compito consiste nella verifica e nell'espressione di un giudizio in merito.

Abbiamo verificato le posizioni e le informazioni del conto annuale mediante procedure analitiche e di verifica a campione.

Abbiamo inoltre giudicato l'applicazione dei principi contabili determinanti, le decisioni significative in materia di valutazione, nonché la presentazione del conto annuale nel suo complesso. Siamo dell'avviso che la nostra verifica costituisca una base sufficiente per la presente nostra opinione.

La Fondazione chiude l'esercizio contabile 2014 con un avanzo di Chf 2'385.82.

Il patrimonio netto della fondazione, dopo la capitalizzazione del risultato d'esercizio, risulta un avanzo positivo per Chf. 87'435.47.

Subordinatamente alla formalizzazione di quanto sopra, raccomandiamo di approvare il conto annuale a voi sottoposto.

Con la massima stima

Alba Advisors SA

Dir. Memmi Fava

Allegati:

- bilancio
- conto economico

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 2014

**BLACKSWAN FONDAZIONE**  
Via Cantonale 26  
**6948 Porza**

Data di stampa 11 giugno 2015/08:43:59

Contabilità 2014 dal 1.1.2014 al 31.12.2014

## BILANCIO patrimoniale al 31.12.2014

Conto	Descrizione	Dare (CHF)	Avere (CHF)	Saldo valuta
<b>ATTIVI</b>				
<b>10</b>	<b>Sostanza circolante</b>			
<b>100</b>	<b>Mezzi liquidi</b>			
1020	Banca BSI c/ 414 AA	99'828.63		
1021	Banca BSI c/ 414 AB	60.40		
1030	PayPal	51.63		
1031	PayPal EUR	585.63		482.15 D EUR
	<i>Totale Mezzi liquidi</i>	<i>100'526.29</i>	<i>0.00</i>	
	<b>Totale Sostanza circolante</b>	<b>100'526.29</b>	<b>0.00</b>	
<b>11</b>	<b>Sostanza fissa</b>			
1105	Mobilio e macchine ufficio	6'020.00		
1106	Hardware e Software	910.00		
	<b>Totale Sostanza fissa</b>	<b>6'930.00</b>	<b>0.00</b>	
	<b>Totale ATTIVI</b>	<b>107'456.29</b>	<b>0.00</b>	
<b>PASSIVI</b>				
<b>20</b>	<b>Capitale di terzi</b>			
<b>200</b>	<b>Debiti a breve termine</b>			
2000	Creditori		12'020.82	
	<i>Totale Debiti a breve termine</i>	<i>0.00</i>	<i>12'020.82</i>	
<b>209</b>	<b>Transitori</b>			
2090	Transitori passivi		2'000.00	
2095	Accantonamento imposte		6'000.00	
	<i>Totale Transitori</i>	<i>0.00</i>	<i>8'000.00</i>	
	<b>Totale Capitale di terzi</b>	<b>0.00</b>	<b>20'020.82</b>	
<b>21</b>	<b>Capitale proprio</b>			
2150	Risultati riportati		85'049.65	
2170	Risultato d'esercizio		2'385.82	
	<b>Totale Capitale proprio</b>	<b>0.00</b>	<b>87'435.47</b>	
	<b>Totale PASSIVI</b>	<b>0.00</b>	<b>107'456.29</b>	
<b>Totale a pareggio</b>		<b>107'456.29</b>	<b>107'456.29</b>	

# FINANCIAL REPORT 2014

**BLACKSWAN FONDAZIONE**  
Via Cantonale 26  
**6948 Porza**

Data di stampa 11 giugno 2015/08:45:15

Contabilità 2014 dal 1.1.2014 al 31.12.2014

## CONTO economico dal 1.1.2014 al 31.12.2014

Conto	Descrizione	Dare (CHF)	Avere (CHF)
<b>COSTI PER MATERIALE E MERCI</b>			
	<b>Totale COSTI PER MATERIALE E MERCI</b>	<b>0.00</b>	<b>0.00</b>
<b>COSTI D'ESERCIZIO</b>			
<b>41</b>	<b>ALTRI COSTI D'ESERCIZIO</b>		
4210	Interessi e spese diverse	811.03	
4220	Spese bancarie	399.00	
4250	Differenze di cambio	674.30	
4400	Ammortamenti	2'970.00	
4700	Materiale ufficio e stampati	507.25	
4703	Spese Gala	1'100.00	
4704	Promozione e marketing	2'149.08	
4706	Spese brand, web domains	100.00	
4720	Spese telefoniche/fax/postali	7'344.00	
4730	Spese TforT	4'676.82	
4760	Spese di rappresentanza	5'668.51	
4770	Costi amministrativi e consulenze	5'400.00	
4771	Tasse, Fiduciaria, membership	2'376.00	
4802	Sito web e webmaster	754.19	
4830	RE(ACT) congress	125'280.15	
	<b>Totale Altri costi d'esercizio</b>	<b>160'210.33</b>	<b>0.00</b>
	<b>Totale COSTI D'ESERCIZIO</b>	<b>160'210.33</b>	<b>0.00</b>
<b>RICAVI D'ESERCIZIO</b>			
<b>60</b>	<b>Ricavi da vendite</b>		
<b>600</b>	<b>Ricavi da vendite</b>		
6004	Donazioni libri ricette		410.00
6006	Donazioni PayPal		20'319.41
6007	Grants	18'320.32	
6008	Donazioni varie		38'880.60
6009	Donazioni Libro Rare Disease		166.46
6010	Donazioni Progetto STOP RARE		98'380.00
6011	Donazioni Particolari (Azioni esterne, lasciti, decessi)		20'600.00
6012	Donazioni Gala/Eventi		2'160.00
	<b>Totale Ricavi da vendite</b>	<b>18'320.32</b>	<b>180'916.47</b>
	<b>Totale Ricavi da vendite</b>	<b>18'320.32</b>	<b>180'916.47</b>
	<b>Totale RICAVI D'ESERCIZIO</b>	<b>18'320.32</b>	<b>180'916.47</b>
	<b>Risultato d'esercizio</b>	<b>2'385.82</b>	
	<b>Totale a pareggio</b>	<b>180'916.47</b>	<b>180'916.47</b>

# 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

## NEW PARTNERSHIP

E-RARE is the European Commission consortium of national funding bodies for research on rare diseases. The consortium comprises 25 institutions from 17 European, associated and non-European countries. E-RARE encourages excellent research groups to collaborate transnationally in the area of rare diseases. In this way the knowledge of the research groups is combined, doubling of efforts are avoided

and the resources of the funding agencies are leveraged. The collaborations between the funding agencies and between the researchers result in an accelerated development of diagnostic tools and therapies for people with a rare disease.

In 2014 the BLACKSWAN Foundation and E-RARE became official partners. They are now joining their efforts for the organization of the 3rd edition of the RE(ACT) Congress in 2016 and the promotion of the RE(ACT) Community so as to increase knowledge sharing and collaborations among researchers working in the rare disease field

The BLACKSWAN Foundation welcomes this new important partnership and is honoured to work with E-RARE.



ProRaris





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[www.blackswanfoundation.ch](http://www.blackswanfoundation.ch)

(secured payment by credit card or PayPal)

### GIVE BY USING ORANGE BVR:

CCP: 69-50-1

In favour of: BLACKSWAN Foundation

Bank Account: A127414AA

IBAN: CH39 0846 5000 A127 414A A

### BY BANK TRANSFER:

BLACKSWAN Foundation,

BSI SA,

CH-6900 Lugano

IBAN: CH39 0846 5000 A127 414A A

SWIFT-BIC: BSILCH22

Clearing: 8465

### 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, CH-1418 Vuarrens

Switzerland

[contact@blackswanfoundation.ch](mailto:contact@blackswanfoundation.ch)

[www.blackswanfoundation.ch](http://www.blackswanfoundation.ch)

[www.react-community.org](http://www.react-community.org)

[www.react-congress.org](http://www.react-congress.org)

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[www.facebook.com/REACT.community.official](http://www.facebook.com/REACT.community.official)

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[twitter.com/react\\_community](https://twitter.com/react_community)

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