

# BLACKSWAN FOUNDATION

**ANNUAL REPORT  
2013**

**SWISS FOUNDATION FOR RESEARCH ON ORPHAN DISEASES**

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## The President's Editorial

The scientific and medical sector is constantly evolving and research is developing cutting-edge therapies. Significant progresses have been made, still, much more remains to be done to get new treatments for the vast majority of rare diseases.

For these reasons, in 2013 the BLACKSWAN Foundation decided to create an online platform, the RE(ACT) Community, to allow researchers and patients to share scientific information and knowledge but also to finance research projects thanks to a crowdfunding facility integrated in the platform.

Since its launch, the RE(ACT) Community has developed important collaborations with international strategic partners such as E-RARE (European Commission Program ERA-Net for Research Programs on Rare Diseases) and EURORDIS (Non-governmental patient-driven alliance of rare diseases' patient organisations).

In parallel with this project, the BLACKSWAN Foundation has undertaken other initiatives to collect funds for scientific research and create awareness on rare and orphan diseases. We still need your support!

On behalf of rare diseases' patients and myself I would like to thank you for your generosity and I hope that in the future you will continue to support this important cause.

Sincerely yours,

Olivier Menzel



## The Foundation in Brief

Orphan diseases are largely ignored by private and public funders and although considered rare, it is estimated that as many as 500'000 Swiss citizens and 35 million Europeans may suffer from one of these disorders (6-8% of the Swiss and of the European population). Switzerland has no public funding policy for rare and orphan diseases at the moment, in spite of being a leader in biotechnology and pharmaceutical research.

The BLACKSWAN Foundation is a Swiss foundation created to contribute to the development of research on rare and orphan diseases in Switzerland and worldwide. The principal mission of the BLACKSWAN is to collect funds that will be entirely devoted to research projects. These projects are selected by a scientific committee composed by internationally recognized experts. Another important objective of the Foundation is to improve the public understanding of these disorders promoting information campaigns on rare diseases.

Since April 2010 the BLACKSWAN Foundation is officially inscribed in the Swiss commercial register. The Foundation is supervised by the competent authority at the Swiss Federal Department of Home Affairs (FDHA) and recognized as a public utility Foundation. The Foundation meets the legal criteria for tax exemption.

## The Research

Research in rare and orphan diseases faces two major hurdles:

Epidemiology: low number of subjects/patients.

Financial constraints: these diseases are considered economically uninteresting.

Therefore, research focuses on:

- Basic research
- Clinical research
- Therapeutic trials

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. This combined effort allows for an exchange of multidisciplinary expertise and best practices.

To motivate members of the industry to enter this small market, EU Regulation No. 141/2000 provides the opportunity to develop market “niche”, particularly interesting for small and medium enterprises. Even though this policy has enabled the development of orphan drugs, most rare diseases are still without effective treatment.

It is therefore imperative to strengthen links between universities and industry to capitalize on the results of academic research by using them to develop new diagnostic and therapeutic tools.



## Support to Scientific Research

### **The RE(ACT) Community:**

The RE(ACT) Initiative, started in 2011, is structured on the RE(ACT) Congress and on the online RE(ACT) Community. Its mission is to strengthen the synergies between researchers and other stakeholders that are related to different extents with rare and orphan diseases. The RE(ACT) Congress is organized every two years and brings together world leaders researchers and young scientists from stem cell, cell biology, gene therapy, human genetic, or therapeutic applications to present state-of-the-art research, to discuss results and to exchange ideas.

The online RE(ACT) Community has been developed in 2013 and facilitates continuous collaboration between researchers on projects, as well as communication amongst patients and between patients and researchers, information gathering, crowdfunding for research projects, and promotes opportunities to optimize synergies between stakeholders, from patient organizations to academic institutions, centers of expertise, health industry, regulators and policy makers.

The main objective of the RE(ACT) Community is to facilitate cooperation on rare disease's research worldwide and thus increasing the delivery on the market of new molecules and therapies for millions of patients affected by rare and orphan diseases and to create innovation in this sector.

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

The online RE(ACT) Community is organized around four main axis dedicated to research on rare and orphan diseases: Learn, Meet, Share and Support. Learn from the knowledge and experience of other researchers and patients; meet other researchers and facilitate the exchange of information between researchers and patients; share scientific knowledge and experience and; financially support research projects.

The majority of the interactions are developed around the "Disease Dossiers". A Disease Dossier becomes unlocked with at least 15 followers. 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 RE(ACT) Community is supported by a Secretariat and a Scientific Advisory Board. The Secretariat deals with the overall coordination and administration of the Community including memberships, the organization of the RE(ACT) Congresses and other conferences and meetings both at national and international level. The Secretariat acts as the main reference point for all members, sends out newsletters with relevant information on RDs and liaises with the Scientific Advisory Board.

The main role of the Scientific Advisory Board is to assure internal control of the scientific contents exchanged in the Community, to encourage discussions and recognize excellence in research. The Scientific Advisory Board is also responsible, in collaboration with the Scientific Committee of the BLACKSWAN Foundation, to evaluate the eligibility of a project to crowdfunding in order to guarantee to the public high standards of quality for the projects supported by the Community.

The public Beta-version release of the RE(ACT) Community is planned for March 2014 with the opening of the second edition of the RE(ACT) Congress.

## Initiatives to collect funds and create awareness

### Gala Dinner “Rare Night”

On the 28<sup>th</sup> of February, 140 guests took part to the “Rare Night” fundraising gala dinner organized by the BLACKSWAN Foundation in Vevey, Switzerland. The event aimed to raise funds for research on Atypical Rett Syndrome and increase awareness on rare diseases through an original tombola and the auction of a painting.

15 Swiss celebrities took part to the event and offered to share a unique moment with the winners of the tombola; among them, the world champion figure skater Stéphane Lambiel, the comic actress Brigitte Rosset, the model Sabrina Guilloud, the show man David Cunado and the comic actors Yann Lambiel, Frédéric Recrosio and Cuche et Barbezat.

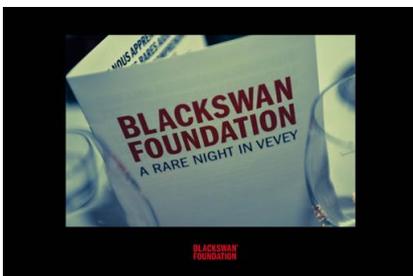
The French painter performer Franck Bouroullec, who is also a BLACKSWAN’s ambassadors, painted a 4 m<sup>2</sup> portrait of Salvador Dalí in less than five minutes. The painting was auctioned during the dinner.

Total amount raised: CHF 50’000

Link to the dinner video:

<https://www.youtube.com/watch?v=6tn2lLk5hzM>

Photos : <http://www.flickr.com/photos/blackswanfoundation/sets/72157632982703029/>



## Help Pain

From February 23, to the end of the month, the Foundation, in collaboration with the bakery shops Les Pains Paillasse and the Lions Clubs of Switzerland organized a solidarity campaign to support rare diseases.

Considering rare diseases as a whole, they affect 1 in 15 people and more than 500'000 citizens present a rare condition in Switzerland. So, in order to make everyone concerned about this problematic and reach people's attention, the Foundation choose to target a daily food: the bred. During one week the bakery shop sold one type of bred in a special packaging (HELP PAIN) in favor of the cause of rare diseases.

On the 9th of March, the Lions Clubs sold the HELP PAIN on the streets of the whole Suisse Romande.

Total amount raised: CHF 20'600



## T for T – T-shirt 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 disease as well as about research needs and to collect funds to support the discovery and development of new therapies for these diseases.

The ambassador and artistic director of the campaign is Franck Bouroullec who decided to put his talent at the service of this cause. Franck is an exceptional painter-performer and his 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 logo are available on a limited series of T-shirts as part of the campaign T for T.

The year 2013 has seen the launch of the campaign and the creation of an online shop. T-shirts can be ordered at: <http://tfortherapy.org>



## Gala evening “Ice & Fire”

On the 30th of November the Jeune Chambre International (JCI) of Geneva organized an Ice & Fire dinner show in favor of the BLACKSWAN Foundation.

The Gala Dinner Event of approx. 300 guests offered a gastronomic buffet, a fashion show, various artistic performances and an auction of which the benefits were given to the Foundation.



## Participation in the writing of the Book

“RARE DISEASES Challenges and Opportunities for Social Entrepreneurs“

Edited by Nicolas Sireau, AKU Society – UK

There are 7,000 rare diseases and only 200 rare diseases have approved treatments. In recent years, there has been a surge of interest from business and social entrepreneurs in the field of health – including looking at ways to treat rare disease patients better and faster.

This book presents some of the latest developments in the world of rare disease entrepreneurship from a global group of experts. The BLACKSWAN Foundation was invited to write a chapter.

It examines the topic from the business angle, considering the drug development process and providing case studies of successful orphan drug enterprises. It also looks at rare diseases from the perspective of the patient, analyzing the growing rare disease patient movement, a successful patient group that uses social enterprise techniques, and chapters on key requirements for helping patients with rare diseases through registries and centers of excellence.

The book will be an essential toolkit for social and business entrepreneurs who are interested in the world of rare/orphan diseases. It has the rigor of an academic publication, along with the clarity of a lay publication. An original and timely book, Rare Diseases will help to add knowledge and awareness to a vastly under-published subject.

A copy of the book can be ordered at: <http://shop.blackswanfoundation.ch>

# Financial report 2012



# BLACKSWAN FONDAZIONE

Porza

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RAPPORTO DELL'UFFICIO DI REVISIONE

ESERCIZIO 2013

Alba Advisors SA

Via Carlo 2 - CP 5117 - 6900 Lugano (CH) - Tel. +41(0)59123610 - Fax +41(0)59123617  
info@albadvisors.ch - www.albadvisors.ch - No. TVA: CHE-108.642.160



Lugano, 24 settembre 2014

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

**RAPPORTO DI REVISIONE  
ESERCIZIO 2013**

Nella nostra qualità di Ufficio di controllo abbiamo verificato l'esattezza dei conti della vostra Fondazione, per l'esercizio chiuso al **31 dicembre 2013**.

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.

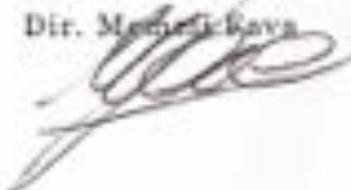
Abbiamo verificato le posizioni e le informazioni del conto annuale mediante procedure analitiche e di verifica a campione.

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 2013 con un avanzo di Chf 61'112.05.

Il patrimonio netto della fondazione, dopo la capitalizzazione del risultato d'esercizio, risulta un avanzo positivo per Chf. 85'049.65.

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

Con la massima stima  
Alba Advisors SA  
Dir. 

**Allegati:**  
- bilancio  
- conto economico

Alba Advisors SA

Via Curti 3 - CP 8117 - 6900 Lugano (CH) - Tel. +41(0)91 912.56.10 - Fax +41(0)91 912.56.17  
info@albainditors.ch - www.albainditors.ch - No. IVA / CHE-108.642.100

## BILANCIO patrimoniale al 31.12.2013

Conto	Descrizione	Debiti (CHF)	Avari (CHF)
<b>ATTIVI</b>			
10	Sostanza circolante		
100	Mezzi liquidati		
1020	Banca BSI c/ 414 AA	87076.47	
1021	Banca BSI c/ 414 AB	100.40	
1030	PayPal	1706.53	
	<b>Totale Mezzi liquidati</b>	<b>84783.40</b>	<b>0.00</b>
	<b>Totale Sostanza circolante</b>	<b>84783.40</b>	<b>0.00</b>
11	Sostanza fissa		
1102	Mobili e macchine ufficio	8600.00	
1106	Hardware e Software	1300.00	
	<b>Totale Sostanza fissa</b>	<b>9900.00</b>	<b>0.00</b>
	<b>Totale ATTIVI</b>	<b>94683.40</b>	<b>0.00</b>
<b>PASSIVI</b>			
20	Capitale di terzi		
200	Debiti a breve termine		
2000	Creditori		433.75
	<b>Totale Debiti a breve termine</b>	<b>0.00</b>	<b>433.75</b>
209	Transazioni		
2090	Transazioni passivi		7400.00
2095	Accantonamento imposte		6000.00
	<b>Totale Transazioni</b>	<b>0.00</b>	<b>9400.00</b>
	<b>Totale Capitale di terzi</b>	<b>0.00</b>	<b>9833.75</b>
21	Capitale proprio		
2130	Risultati riportati		27937.60
2170	Risultato d'esercizio		67117.05
	<b>Totale Capitale proprio</b>	<b>0.00</b>	<b>87949.65</b>
	<b>Totale PASSIVI</b>	<b>0.00</b>	<b>94683.40</b>
	<b>Totale a pareggio</b>	<b>94683.40</b>	<b>94683.40</b>

## CONTO economico dal 1.1.2013 al 31.12.2013

Conto	Descrizione	Debiti (CHF)	Averri (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>			
40	<b>ALTRI COSTI D'ESERCIZIO</b>		
4210	Interessi e spese diverse	67.87	
4220	Spese bancarie	315.60	
4701	Promozioni - stampati	188.80	
4712	Libri (Rare Dissets)	951.00	
4713	Spese Gala	24542.50	
4714	Promozione e marketing	2686.42	
4719	Spese libri ricotte	10609.39	
4760	Spese di rappresentanza	5113.40	
4770	Costi amministrativi e consulenze	2000.00	
4802	Sito web e webmaster	1478.21	
4830	RE(AC)T congress	45449.00	
4900	Imposte	6000.00	
	<b>Totale Altri costi d'esercizio</b>	<b>99694.26</b>	<b>0.00</b>
	<b>Totale COSTI D'ESERCIZIO</b>	<b>99694.26</b>	<b>0.00</b>
<b>RICAVI D'ESERCIZIO</b>			
60	<b>Ricavi da vendite</b>		
6000	<b>Ricavi da vendite</b>		
6000	Donazioni e contributi		875.51
6002	Donazioni RE(AC)T congress		47000.00
6003	Donazioni libri		674.00
6004	Donazioni libri ricotte		12290.00
6006	Donazioni PayPal		450.00
6008	Donazioni varie		57899.80
6009	Donazioni Libri Rare Disette		1737.00
6012	Donazioni Gala		47880.00
	<b>Totale Ricavi da vendite</b>	<b>0.00</b>	<b>160806.31</b>
	<b>Totale Ricavi da vendite</b>	<b>0.00</b>	<b>160806.31</b>
	<b>Totale RICAVI D'ESERCIZIO</b>	<b>0.00</b>	<b>160806.31</b>
	<b>Risultato d'esercizio</b>	<b>61772.05</b>	
	<b>Totale a pareggio</b>	<b>160806.31</b>	<b>160806.31</b>

# Informations

## Remerciements / Acknowledgment

Notre sincère gratitude s'adresse à tous nos généreux donateurs, sponsors, partenaires et bénévoles qui ont soutenu notre action.

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

## Réseau / Network

Affiliés à / Affiliation

- ProRaris - alliance Suisse maladies rares / [Swiss rare disease alliance](http://www.prorarais.ch) (www.prorarais.ch)
- EURORDIS - alliance européenne des organisations de patients / [European alliance of patient organizations](http://www.eurordis.org) (www.eurordis.org)

## Contacts et coordonnées bancaires / Contacts and bank details

BLACKSWAN Foundation

Chemin de la Riaz 11

CH-1418 Vuarrens

contact@blackswanfoundation.ch

Facebook: <https://www.facebook.com/Blackswan.Foundation>

Twitter: <http://twitter.com/BLACKSWANFound>

Foursquare: <https://foursquare.com/blackswanfound>

Youtube: <http://www.youtube.com/blackswanfoundation>

## Donations

### En ligne / Online

[www.blackswanfoundation.ch](http://www.blackswanfoundation.ch) (paiement sécurisé en ligne par carte de crédit ou avec PayPal / [secure payment by credit card or PayPal](#))

### Don par bulletin de versement / Give by using orange BVR

CCP: 69-50-1 En faveur de / [In favour of](#) BLACKSWAN Foundation

Compte / [Account](#): A127414AAIBAN: CH39 0846 5000 A127 414A A

### Par virement bancaire / By bank transfert

BLACKSWAN Foundation, BSI SA, CH-6900 Lugano

IBAN: CH39 0846 5000 A127 414A A

SWIFT-BIC: BSILCH22

Clearing: 8465

### Donation par SMS (uniquement en Suisse) / Donation by SMS (Switzerland only)

Donation par SMS au 339: BSF suivi du montant. Par exemple: pour un don immédiat de CHF 100, envoyez BSF 100 au 339.

[Donation by SMS to 339:BS followed with an amount. For example: for an immediate donation of 100 CHF, send BS 100 to 339.](#)

## Membres de la Fondation / Members of the Fondation

### Conseil de Fondation / Board of Directors

Président et Fondateur / President and Founder

DR OLIVIER MENZEL, PhD. MBA - Vuarrens

Membres / Members

VINCENZO PIANTEDOSI, BSI SA - Lugano

MASSIMO RICCARDI, Studio Legale Riccardi - Lugano

### Comité Scientifique / Scientific Advisory Board

Présidente / President

PROF BARBARA WILDHABER MD, PD; Children's Hospital, Geneva, Switzerland

Membres / Members

PROF STYLIANOS E. ANTONARAKIS MD, PhD; Head of the Dept. of Medical Genetics and Development, Geneva, Switzerland

DR JACQUES BIRRAUX MD; Children's Hospital, Geneva, Switzerland

PROF BRUNO DALLAPICCOLA MD; Scientific Director of Pediatric Hospital Bambino Gesù, Rome, Italy

DR CELIA DELOZIER-BLANCHET PhD; Director of Clinical Services, University of California, USA

DR MARISA JACONI PhD, MER; University of Geneva, Switzerland

PROF STANISLAS LYONNET MD, PhD; Professor of Genetics, University of Paris - Hospital Necker, France

PROF MARTIN MEULI MD; Head of Department of Pediatric Surgery University Hospital of Zurich, Switzerland

DR MICHAEL NICOLAS PhD; University of Lausanne, Switzerland

PROF ALEXANDRE REYMOND PhD; University of Lausanne, Switzerland

DR PATRICK SALMON Pharm., PhD; University of Geneva, Switzerland

PROF HAMISH S. SCOTT PhD; University of Adelaide, Australia

PROF ETIENNE SOKAL MD; Head of the Pediatric Gastroenterology - Hepatology Unit, Catholic University of Leuven, Belgium