



Using a Design-Build Approach to Improve International ALS Research News Access in Italy

Zichieri, A.D.¹, Conte, S.F.¹, De Rossi, N.¹

1. Associazione conSLAnco Onlus – Terracina (LT), Italy



conSLAnco Founder, Andrea Zichieri, with his son, Mattias, 2016

Introduction

The objective of this work is to improve **accessibility** of real-time online national and international scientific **ALS research news** in Italy. Information access is a challenging endeavour for patients, families, and caregivers in non-English speaking countries. **Design-Build** (Fig. 2) is a project delivery system in which a single entity oversees and executes a project from design to completion. In this project, the Italian ALS community provided critical input and was involved throughout. **Design-Build** ensures quality performance which can save time and money compared to outsourcing the work. Using Design-Build, conSLAnco made four new resources of ALS research news. Community interactions have increased over time.

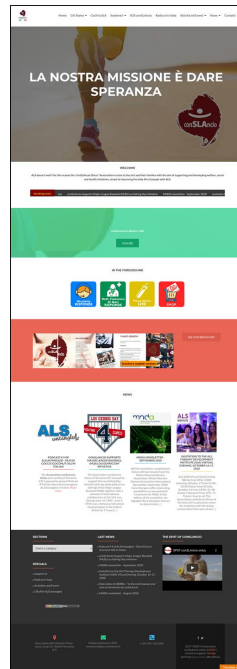


Figure 1. New conSLAnco homepage

1. Italy's First LIVE ALS Clinical Trial Database

Design-Build constructed Italy's First LIVE International ALS Clinical Trial Database (Fig. 3) resulting in a comprehensive listing of daily trial status updates for drug/interventional trials, biomarker/observational trials, and completed trials. <http://www.conslanco.it/proveattive/italy>

- It is user-friendly, fully compatible with desktop computers, tablets, and mobile devices.
- The database allows users to view the clinical trials taking place at sites in, or close to Italy.
- Each trial is linked to the official registry where users can directly access study objectives, eligibility criteria and study contacts.

ULTIMO AGGIORNAMENTO	PROVA	FASE	RECLUTAMENTO	SPONSOR	SEDE
27/10/2020	Il Programma di Medicina con Precisione	NA	●	ALS Therapy Development Institute	Cambridge, MA, USA
14/10/2020	The Precision Medicine Program Ulivo Studies sull'Efficacia e Sicurezza di Raviluzamib nel Partecipanti di SEA	3	●	Alton Pharmaceuticals	ICI Hospital IRCCS Milano, Italia Istituto Auxologico Italiano, Milano, Italia
14/10/2020	Studio sulla Sicurezza dell' Ederavone Orale Somministrato in Soggetti con SEA Safety Study of Oral Ederavone Administered in Subjects with ALS	3	●	Mitsubishi Tanabe Pharma Development America, Inc.	Università degli Studi di Torino - Centro Regionale Esperimenti in ALS (CRESLA) (44 Centri nel Mondo)

Figure 3. Drug/Interventional Trials

2. conSLAnco Caregiver Training Course Series

Designed to precisely integrate with the specific mission of the Association to **support ALS carers and all personnel** when health institutions are unable to do so. The course is available in-person, and online. Its objectives are to:

- Improve the qualitative processes of the procedures that caregivers have to manage, especially at home.
- Instruct caregivers on the latest best practices and guidelines that all medical professionals are obliged to adhere to in order to prevent free interpretation by healthcare providers themselves.
- Provide valuable training on effective communication for positive benefits in the care setting for the psychological well-being of all involved.
- Establish a bridge between families and conSLAnco to develop better intervention protocols that are feasible in the home due to the actions of the healthcare professionals involved.

3. ALSUntangled in Italian

- Podcasts in Italian for the first time.
- An international program that reviews alternative and off-label treatments with the goal of helping patients and families make more informed decisions.
- <http://www.conslanco.it/alsuntangled/podcasts/italiano/>



4. Website & Social Media

- conSLAnco user-friendly multi-lingual website <http://www.conslanco.it>
- A guide to Edaravone in Italy <http://www.conslanco.it/edaravone/italy>
- Message Banking™, Voice Banking, and Double Dipping, [Introduction and Process Literature in Italian](#): The newest Italian language augmentative communication technology developed in 2019. Message Banking™ allows a patient to record their personal natural voice for use with all communication devices (Comunicare n.39 (dicembre 2019) – Semestrale della Fondazione e del Centro Benedetto D'Intino Onlus).
- Newsletters in Italian
- conSLAnco's Top 5 Things to Follow in ALS (Annual Summary) <http://www.conslanco.it/2020/08/11/5-cose-da-seguire-in-2020/>
- The Motor Neuron Disease Association Research Monthly <http://www.conslanco.it/category/mnda-newsletter/>
- ALS Therapy Development Institute Research News and daily international research news on social media <http://www.facebook.com/conslanco>

ALS Community Interactions

Preliminary data (Fig.4) show a 96% increase of member interactions in Italy and abroad during January to September 2020. Correspondence to conSLAnco indicates increasing educational discussions among members.

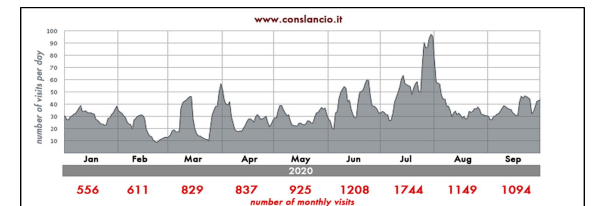


Figure 4. conSLAnco website visits, January - September 2020

Conclusion

The **Design-Build** approach has proven beneficial in improving access to timely national and international ALS research news for conSLAnco. The four resources presented here were constructed within a two-year period. conSLAnco will continue to develop new projects using Design-Build in response to the Italian ALS community's input. Additional national and international collaborations for up-to-date information will also be sought.

Acknowledgements

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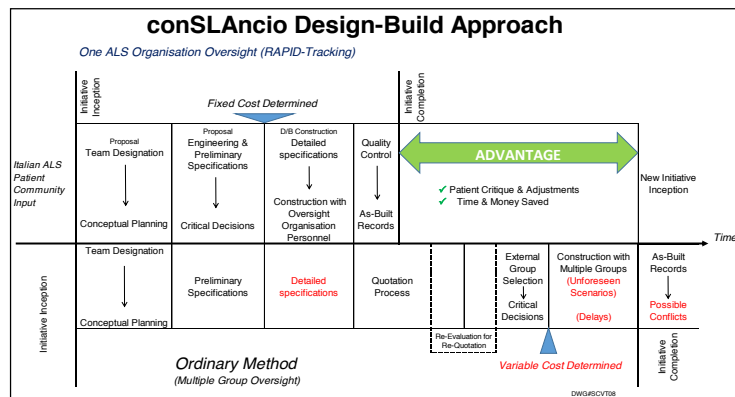


Figure 2. A timeline illustrating a comparison of the conSLAnco Design-Build approach versus an ordinary project delivery sequence.