

# OPERATION ANASTACIA

Project of Brignoles  
Rotary Club

**2021**





## THE ANASTACIA PROJECT

Anastacia Tilotta was born in 2009 with both ears missing and also the ear canal completely closed. This condition called "atresia microtia" causes hearing loss on both sides.

From the age of 3 months old, Anastacia has been equipped with an external hearing device and has been following a normal school program

Her parents learned 2 years ago that a revolutionary surgical procedure of rebuilding a new outer ear (medpor method) and creating an inner canal is performed by 2 very high profile pediatric surgeons at the Palo Alto Ear Institute close to San Francisco Ca.

The medical evaluation of Anastacia including a CT scan indicates that she is an excellent candidate to undergo this surgical procedure

This complex and specialized all day long operation ( 9 hours) will be performed at Palo Alto Ear Institute on July 15<sup>th</sup> 2021 with 4 post treatment appointments in Los Angeles during the 4 following weeks .

## BRIGNOLES ROTARY CLUB:

Brignoles is a small French town of approx 20,000 inhabitants located in Provence between Marseille and Nice

Our club was created in 1952 and includes 27 members. It is a very active club whose main actions are directed to Africa for water filtration equipment and to our region: assistance to people affected by river flood, supply of computer tablets for residents of nursing homes, planting olives trees, installing defibrillators and assistance to children. This year we decided to help Anastacia's family .

We also welcomed many youth exchange students in the previous year.

## ANASTACIA'S FAMILY:

**Family name: Tillota**

Anastacia is on the left of her father

Franck, with his spouse Alexandra, their elder daughter Tatiana aged 15 and Anastacia aged 12.





### **ALEXANDRA:**

Alexandra has been working as an accountant for 14 years in a material sales company where she is also in charge of human resources. Franck met Alexandra in Russia, as he was staying in Saint Petersburg, on an internship, in 1997, a time when Alexandra was his guide (they communicated in English). Her family had just been hit by the financial and monetary crisis. Her father, a biology researcher, and her mother, a calculation engineer, had both lost their jobs and all their savings (due to the inflation and the fact that banks were going bankrupt). There was no unemployment insurance in Russia. This « summer job » enabled Alexandra to provide for the needs of her family. It is to be noted that this crisis caused Alexandra's father's death in 1999.

Alexandra and Franck got married in 2003. They decided to live in Provence where the environment was more favorable (climate, social protection...) in spite of the economical opportunities in Russia: Alexandra was the head of human resources in a big construction company. Alexandra did not speak French.

She learned French with private lessons, and also thanks to a job that Franck found her with the Chamber of Agriculture.

Alexandra had a diploma in economics from a Russian school, she had specialized in accountancy and audit, and the French level equivalent to that would have been 5 years of higher education.. But there was no official recognition of diplomas between France and Russia. Consequently, in 2006, Alexandra registered at the university at Toulon, where she studied business management and where she passed her master's degree with very good results.

She then applied for a job as an accounting assistant with the company Verdi Materiaux, her application was accepted, and she worked her way up in the company.

Level of English: correct, but little conversation practice.



### **FRANCK:**

Franck is the founder and manager of a small dairy sheep breeding company. He has been practicing organic farming since 2014. He loves his job which consists in breeding sheep, manufacturing finished products (cheese, yoghurt, local specialties ...) and selling directly to the consumers, mainly on the two markets in Gareoult (80% of his sales).

After having passed a technician's degree in agriculture, he registered in an engineer's school (ISA Beauvais, called today Unilasalle) and graduated in 1999.

As he was in that school, he spent all his internships abroad, which allowed him to discover other cultures and ways of life, to improve his English, and also to learn the basics of the dialect spoken in Benin, the basics of Khmer, and to learn Russian. Today Franck is fluent in English and Spanish, and does well in Russian.



He started his working life having different jobs in agricultural professional organizations, particularly in the local Chamber of Agriculture. He worked there for 13 years and occupied different positions, his last position being manager. At the beginning, his activity was 80% on-site and 20% administrative tasks.

In the end, the ratio became 80% administrative tasks, which is why he decided to change jobs and do something he liked.

He was encouraged by his wife who stressed the fact that he had the ideal opportunity to change jobs: it was the right time as they got some land (family property) in the Gareoult hill, a place that was perfect for breeding sheep. It was the right time because she was earning wages and could provide for the household.

Franck started from scratch when he created his farm in the forest : the first thing that needed to be done was remove the brush, then cut the trees, do the earthworks ,install two greenhouses and the cheese production room.

When his herd of sheep arrived, it was winter and he had no electricity, so he had to hand milk the ewes and to bring the milk to a colleague in order to produce dairy products. The whole family was committed in the work, keeping the sheep on the hill, manufacturing the first yoghurts in the oven at home, conditioning the products and preparing the first markets.

Franck learned on-the-job the skills of a builder, electrician, carpenter, lumberjack, seller ... He encountered lots of difficulties in the first years of his activity – the electrical network connection was delayed, he worked alone 14 hours a day seven days a week without the help of an employee, he had to do with the presence of wolves which attacked his herd during the first Summer making him lose 45% of the sheep – all this did not discourage him. Thanks to his passion and to his family support, he managed to persevere and achieve his dream.

His herd grazes on the hills in Gareoult all year round except during three months in Summer when the sheep are taken to other fields in the mountains and are kept by a shepherd (which will allow Franck to go to the USA for Anastacia's operation) . The sheep are fed naturally on the hills all year round.

The milk, cheese, yoghurts are organic.

Franck has experimented a lot in order to find ways of limiting the use of agricultural inputs and to be as locally authentic as possible.

He has quickly gained loyal customers (most of them live in his native village) thanks to the quality of his products, and also to the pastoral breeding he puts into practice. The sheep are happy, their natural rhythm is respected. That is probably the reason why his dairy products are so tasty.

Level of English: Good , and knowledge of technical English.



## **TATIANA:**

Tatiana is the couple's elder daughter, she is 14 (date of birth: 2006/05/05)

She is in 9th grade in the middle school of Gareoult and she has excellent school results ( 18,3 / 20). Although she is a little young to have a precise idea of the career she will choose, what attracts her at the moment is becoming either an architect or a chef specialized

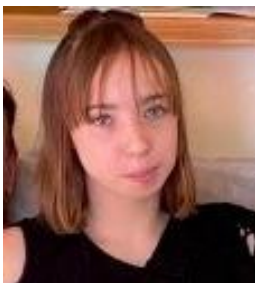


in confectionery. At school, discovery sessions are compulsory in 9th grade, and she has chosen to spend her session with a firm of architects in Brignoles, ARC'H.

Tatiana practices hand-ball, badminton, skiing, roller-skating and ice skating. She plays the guitar and she sings. As for her interest in confectionery, she takes lessons on specialized internet sites and practices at home. Tatiana loves reading comic's books and novels. She is particularly fond of fantasy novels.

She is rather timid and discreet, unlike her sister.

Although they are quite different, the two sisters are very close and united.



### **ANASTACIA:**

Anastacia was born in Brignoles on Jan 2<sup>nd</sup> 2009; She is affected by atresia microtia, a disease which affects one child out of 50,000.

In 2009, an urgent appointment with a specialised pediatric doctor in Marseille allowed the family to be informed about the situation, to explain the problem and more important to take ASAP the necessary actions: audiogram hearing test at 6 weeks old , external hearing equipment installation when she was 10weeks old , first examinations and operations, speech therapy.

Life during the first 8 years of Anastacia was organized around the appointments for diagnostic examinations, planning and organizing surgical interventions, audiograms. But also every week some speech and psycho logic therapy in Toulon in a care department dedicated to the assistance of children and families affected by such kind of situation.



These are the operations that Anastacia underwent between 2012 and 2015 in France, because in addition to her hearing problem, she has some malformations in her mouth, including an asymmetry of the jaw and face:

- closure of a submucosal veolar division (double Z opposite technique) - 2012,
- fitting of a BAHA Attract straight (Cochlear) bone conduction and bone anchored hearing aid with a subcutaneous magnetic part - 2015,
- left mandibular distractor placement - 2015.



This latest operation, very delicate and above all very painful, was only a first step to prepare the ground for a mandibular levelling surgery and genioplasty which will take place around the age of 15, followed by a long orthodontic treatment afterwards in order to align both jaws but also to redesign the chin with the hope of improving the joint.

Today Anastacia suffers from some speech problems for some sounds produced with the rear part of her tongue [t], [s], [ʃ], [z], [d], [n], [ʒ], [l]. She has been benefiting from some speech therapy since she was 36 months old, which requires a lot of time and organizing for the parents. The purpose of this therapy is to correct her dysfunctional swallowing, the low and in front lingual position and to improve her oral ventilation. The parents also decided to give her some speech therapy in Russian language via internet, in order to get some training for the specific sounds of this language (the r pronunciation using the front of the tongue) but also to improve the use of her mother language

Anastacia made a lot of progress in speech, but she needs to make a lot of efforts with her tongue and lips to produce some particular sounds which is not natural and consequently tiring for her. She must make much more effort than other children to listen, speak and to be understood by people.

Since the beginning, her parents have decided to educate Anastacia as a normal child, they do not consider her as an handicapped person. They are convinced that this choice will allow her to become stronger and help her thrive. They dedicate more time to her for medical processes and for school, but she has always followed the same educational program as her elder sister Tatiana and the same after-school activities and sports.

Since she was a child, Anastacia has surprised people with her physical ability, she started walking when she was 9 months old, she was able to ride a scooter when she was 2, practice skiing and roller skating when she was 3 and she could ride a bicycle when she was only 4 years old. Now she enjoys dancing and progresses quickly when she practices dancing, skiing, snowboarding or skateboarding and other sports that her parents present her like Hand Ball (N°7 on the picture) or climbing.





Despite the absence of external and middle ear, Anastacia has a good musical sense: she loves listening to music, she plays the guitar and drum set and she sings. She took some theater lessons and played her first roles 2 years ago.

Anastacia has some artistic skills, doing drawing and painting, hand craft and knitting, she wishes to start pottery.



This year Anastacia is in 6th grade at the middle school of Gareoult (the small city where the family lives, close to Brignoles) and she does not have any problem with her school program. She is equipped with some hearing aid and a Bluetooth microphone used by the teachers to amplify their voice. She needs to make big efforts to follow the class, particularly now as the wearing of masks by the teachers decreases the power of their voice and eliminates any possibility for her to lip-read.

Anastacia is a strong and combative person, she is not afraid of surgery and is not disheartened by pain. She is a very nice girl, open to others, and faithful and also very active, full of energy, funny, rock-and-roll, emotional.

Her physical difference allowed the family to learn a lot of things, in particular tolerance, it made the family stronger and unified, it allowed her parents to meet new people. The parents are sure that they will enjoy good moments in the future, some changes, all the family is progressing with her.

## **THE OPERATION OF ANASTACIA:**

A new method of ear rebuilding called Medpor Method is performed by 2 extremely experienced professors at the Palo Alto ear institute in California. In one highly complex and specialized all day operation, they will be able to create an inner ear canal and a new outer ear for Anastacia from synthetic biomaterial and wrap it in a thin layer of tissue from her own skin

The medical evaluation of Anastacia and her medical records, including an audiogram hearing test and a CT scan indicate that she is an excellent candidate to undergo this unique and life-changing surgical procedure with 60% chances to obtain normal hearing on this side.

This 9-hour-operation performed by Pr J Roberson will take place in Palo Alto, close to San Francisco Ca on July 15th 2021 , and will be followed by 4 post surgical appointments with Dr Reinisch in Beverly Hills Los Angeles from July 18yh to August 4th

The Tilotta Family finances this operation with their own money for an amount of approx 87,000 \$ , they are now negotiating the corresponding personal loan with their bank, as the French social security system does not provide any help to them.

## **THE ACTION OF BRIGNOLES ROTARY CLUB:**

The Rotary club of Brignoles supports the Tilotta Family with 3 actions:

-Trip to the USA and car rental in California: We introduced them to a friend, past president of our club, who is the founder and owner of a travel agency in Brignoles. This Friend and his team will organize the trip for the 4 family members in good conditions and for a reasonable cost. Most of the travelling costs will be financed by our club.

- speaking English: Alexandra will join the English club organized by a rotarian of our club who is an English teacher. The lessons will be orientated to the needs of Alexandra who will be better prepared to communicate in California

-Welcome in USA: We will contact the local rotary clubs as described in the next paragraph

## **NEEDS OF LOCAL SUPPORT**

This trip will be very difficult for the Tilotta family because of the stress due to the surgical operation, the length of their stay in California (5 weeks) and the difficulty of being in a foreign country.

They will be 4 ( 2 parents and 2 daughter) to stay in San Francisco from July 10<sup>th</sup> to 17<sup>th</sup>, then in Los Angeles from July 18<sup>th</sup> to August 4<sup>th</sup> and finally in San Francisco again from August 5<sup>th</sup> to 15<sup>th</sup>.

Consequently, we thought that the friendship and solidarity between the world Rotary clubs could help them a lot and we are calling out your clubs for the following needs :

Welcome them at their arrival at San Francisco airport and support them during their stay : the ideal solution should be to find them a « sponsor » to welcome them , drive them to their lodging , to the hospital for the first day and being their contact in case of any difficulty.

Find some economical and practical lodging solution close to the hospital: the best solution should be a furnished flat suitable for 4 people; it should allow them to have an almost normal family life as this will be a difficult period for them

Welcome them at their arrival in Los Angeles and support them during their stay : the ideal solution should be to find them a « sponsor » to welcome them , drive them to their lodging , to the hospital for the first day and being their contact in case of any difficulty.

Find some economical and practical lodging solution close to the hospital: the best solution should be a furnished flat suitable for 4 people; it should allow them to have an almost normal family life as this will be a difficult period for them

## **CONTACT :**

First of all, we thank you very much for the attention you will bring to our request.

You will find more pictures of the Tillota family and their activities with this link :

<https://photos.app.goo.gl/DseY2nLYrPdBzgvK7>



