

# Sommario Rassegna Stampa

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# Sommario Rassegna Stampa

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Rubrica **ISSIAMO LE VELE - 31 maggio 2022**

Motoresanita.it

26/05/2022

*ISSIAMO LE VELE! VENTO IN POPPA PER LA RICERCA #thinkrare*

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## Da Torre Annunziata a Marsiglia



Mario Santini, chirurgo toracico e prof dell'ateneo Vanvitelli

# Malattie rare, parte la regata della ricerca

Ettore Mautone a pag. 28

# Il mare della speranza

## Malattie rare, la sfida del prof Vele spiegate verso Marsiglia

► Santini, chirurgo e docente della Vanvitelli ► Il via da Torre Annunziata: in 20 porti toccati in navigazione con un amico imprenditore iniziative per sensibilizzare medici e famiglie

**DIAGNOSI SPESSO IN RITARDO DI ANNI A SOSTEGNO DELLA TRAVERSATA UNIVERSITÀ, REGIONE E LEGA NAVALE**

### L'INIZIATIVA

**Ettore Mautone**

Vele spiegate per la ricerca sulle malattie rare: lunedì prossimo salperanno dal porto di Torre Annunziata Mario Santini, chirurgo toracico, docente ordinario all'Università degli Studi della Campania "Luigi Vanvitelli", e l'imprenditore Rosario Gracco. Da vicini di barca, da appassionati di vela e sensibili entrambi - per motivi personali e professionali - al tema delle malattie rare, hanno lanciato l'iniziativa partendo da una chiacchierata avvenuta lo scorso gennaio con Giuseppe Limongelli, responsabile del centro di coordinamento regionale per le malattie rare e collega di dipartimento di Santini. L'idea ha poi "contagiato" altre realtà, italiane e

straniere, e preso progressivamente forma fino a stabilire un'asse con la Direzione generale dell'assessorato regionale campano alla Salute, con il Centro di Coordinamento Malattie rare della Campania, i Coordinamenti Malattie rare delle Regioni Lazio, Toscana e Liguria; e ad ottenere la collaborazione dell'Università Vanvitelli, dell'Università di Marsiglia e della Lega Navale di Torre Annunziata, nonché il supporto di Motore Sanità. La traversata, che si concluderà il 5 luglio nel porto di Marsiglia, sarà affiancata da diverse iniziative e incontri, in occasione delle soste previste in 20 porti. Sarà possibile seguire il viaggio sui canali social creati appositamente e sul sito <https://sito.libero.it/comet333/>.

### GLI SCOPI

L'obiettivo è chiaro: promuovere la conoscenza delle malattie rare e sensibilizzare i medici e le famiglie. «Il nodo - avverte il professor Limongelli - non è tanto lo screening neonatale, che grazie alle nuove leggi è stato reso più capillare presso i centri nascita, quanto il ritardo della diagnosi. Molte patologie infatti sfuggono al riconosci-

mento precoce e arrivano alla diagnosi e alla terapia con un ritardo che va dai 7 ai 10 anni, con gravi conseguenze sul piano clinico e sulla possibilità di minimizzarne gli effetti». Un dato non trascurabile per i numeri totali, che dimostrano come le malattie rare tanto rare non sono. Parliamo infatti di 5 casi su 10mila nati, uno ogni due-mila. Il numero di malattie rare conosciute e diagnosticate oscilla tra le 7.000 e le 8.000 ma è una cifra che cresce con l'avanzare della scienza e, in particolare, con i progressi della ricerca genetica. Stiamo dunque parlando di milioni di persone in Italia e decine di milioni in tutta Europa. Secondo la rete Orphanet Italia, nel nostro Paese i malati rari sono circa 2 milioni: nel 70% dei casi si tratta di pazienti in cui l'esordio avviene in età pediatrica.

### LE TESTIMONIANZE

«La prevenzione e l'informazione sono fondamentali per la cura delle malattie rare», dice il Rettore dell'Università Vanvitelli, Gianfranco Nicoletti. «Iniziative di questo genere sono necessarie e vanno anzi valorizzate e incrementate. Plaudo dunque all'idea dei nostri docenti e al messaggio che essi

porteranno in tutto il Paese». «Sono felice di rendere questo servizio sociale», confessa poi Santini: «Obiettivo di tutto questo è stimolare e far capire l'importanza della ricerca clinica e preclinica». «Abbiamo scelto il mare come veicolo di comunicazione e diffusione di questa campagna per il suo grande impatto sull'idea di libertà oltre ogni vincolo - conclude Antonella Giglio, presidente Lega Navale di Torre Annunziata - il mare unisce, traina, salva. Ha un potere tauturgico». E ieri alla presentazione dell'iniziativa c'è stato spazio anche per testimonianze proposte dalle associazioni coinvolte, tra cui "Uniamo" e "Cittadinanza attiva". Come quella di Adele Marzò, logopedista di 51 anni di Torre Annunziata, che a 33 anni fu colpita da una emorragia cerebrale causata da una malformazione arterovenosa ereditaria rara. Gli unici segni erano stati nella sua vita piccole macchie sulla lingua, il mal di testa e periodici sanguinamenti dal naso. Curata al Cardarelli è stata strappata alla morte e ora con il suo compagno, Orfeo Mazzella, dentista opontino, ha imparato a convivere con la sua patologia diffondendo il mare della speranza.

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**LA PASSIONE**  
 Mario Santini, docente universitario e chirurgo toracico, sulla sua barca a vela. A sinistra un bimbo coinvolto nel progetto di vela-terapia per autistici a Castellammare



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\$O YLD OD FDPDSDJQD GL LQIRUPD]LRQH RUJDQL]DW  
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GHOHJD]LRQH GHOOD /HJD 1DYDOH ,WDOLDQD GL 7F  
ORWRUH 6DQLWj &RQ O1RELHWWLYR GL SURPXRYH  
TXHVWH SDWRORJLH O1LQL]LDWLYD SUHYHGH OD S

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MR TEVXMGSP EVI GSR M TVSKVXWVMS HIRP  
TEVPERHS HIP HIPPE RSTSPSGLMIR QERORMM  
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Û-WWMEQS PI ZIPI :IRXS MR TSTTE TIV PI  
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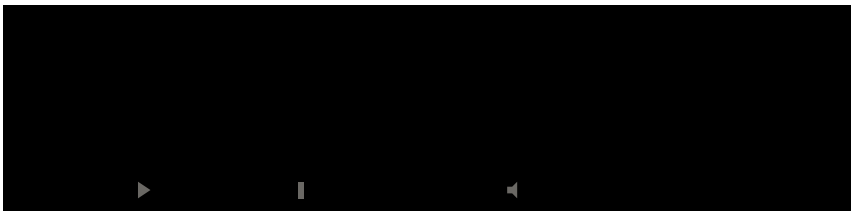
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6DQLWç &RQ OÍRELHWWLYR GL SURPXRYHUH OD FRQRVFLHQ  
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&DPSDQLD &HQWUR 'LUHJLRQDOH ,VROD & GL 1DSROL LC  
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GL 0RWRUH 6DQLWç

8QD PDODWWLD VL GHILQLVFH UDUD TXDQGR OD VXD SUH  
SUHVHQWL VX XQD GDWD SRSRODJLRQH QRQ VXSHUD XQD  
ILVVDWD DOOR SHU FHQWR GHOOD SRSRODJLRQH RVVL  
,O QXPUR GL 0DODWWLH 5DUH FRQRVFLXWH H GLDJQRVWL  
XQD FLIUD FKH FUHVFL FRQ OÍDYDQJDUH GHOOD VFLHQJD I  
ULFHUF D JHQHWLFD 6WLDPR GXQTXH SDUODQGR GHO  
PDODWL PD GL PLOLRQL GL SHUVRQH LQ ,WDOLD H DGGLU  
/D SRVLELOLWç GL DWWXDUH LQWHUYHQWL WHUDSHXWLF  
OR VWDWR GL VDOXWH H OD TXDOLWç GL YLWD GHO SDJLH  
SURPXRYHUH OD FRQRVFLHQJD H OD GLDJQRVL SUHFRFH SH

İ1HJOL XOWLPL DQQL OD 5HJLRQH &DPSDQLD KD IDWWR HORIPI SDVVI LO DYDOWI OHO  
0DODWWLH 5DUH DWWUDYHUVR XQD SURJUDPPDJLRQH PLU  
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GHFUHWL YROWL DOOÍDSSURYDJLRQH GHO 3LDQR 5HJLRQD  
,QROWUH D SDUWLUH GDO a VWDWR ULRUJDQLJJDWR LO  
FKH KD WURYDWR XQD QXRYD FROORFDJLRQH SUHVVR OÍ\$2  
GHO 3URIHVVUR \*LXVSSH /LPRQJHOOL 4XHVWR SURJHWVI  
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İ,VVLDPR OH YHOH 9HQWR LQ SRSSD SHU OD 5LFHUF D WK  
GL XQ PHGLFR H GL XQ LPSUHQGLWURUH FDPDQR GL XQLU  
ELVRJQR TXDVL XQİPHUJHQJD VRFLDOH TXHOOD GL IDUH  
GLVDELWLWç H GHOOH 0DODWWLH 5DUH QHOOD FRPXQLWçE  
\*LXVHSSH /LPRQJHOOL 'LUHWWURH &HQWUR GL &RRUGLQD  
&DPSDQLD İ'D XQD VHPSOLFH FKLDFFKLHUDWD FRQ ORUR  
TXHVWR SURJHWWR DPDLJLRVR D WDSSH FKH YHGUç LPSH  
UHJLRQL H OH 8QLYHUVLWç FKH KDQQR GDWR LO SDWURFL  
SRUWDQGR DYDQWL XQ PHVVDJJLR SHQVD UDUR SHQVD D

1XRYH (YLGHQJH 1HOOD \*H  
&DWHWHUL 9HQRVL 3HULIH  
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,O 5ROH 0RGHO

İ/D SUHYHQJLRQH H OİLQIRUPDJLRQH VRQR IRQGDPHQWDOL

GHWRR LO  
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**\$EELDPR D FXRUH OD W**

1RL BRVWUL SDUFWQYUDPR H R DFFHGLDPR DOOH LQIRUPDJLRQL VX  
WUDWWLDPR L GDWL SHUVRQDOL FRPH JOL LGHQWLİFDWRUL XQL  
SHUVRQDOLJJDWL PLVXUDJLRQH GL DQXQQL H FRQWHQXWL DSSU  
&RQ LO WXR FRQ QVWRU OSDUW QBR XWLQJJDWL GDWL GL JHRORF  
SUHFLVL DWUDYHUVR OD VQD WİPQWL YDİ XGL OS RVİLLWDFR  
&OLFFDQGR VXO OLQN İRQ DFFHWWDUH H FKLXGLİ YHUUDQQR DS  
FRQVHQVR SHU L FRNLH WUDQQH FKH SHU TXHOOL WHFQLFL  
3XRL FDPDLUH OD WXV VFHOWD LQ TXDOVLVL PRPHQR QHO QR

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İ6RQR İHOLFH GL UHQGHUH TXHVWR VHUYLJLR VRFLDOH D F  
2UGLQDULR GL &KLUXUJLD 7RUDFLFD GHOOİ8QLYHUVLWç GHJOL 6WXGL GHOOD &DPSDQLİ  
QRQFK« DSSDVLRQDWR YHOLVWD FKH FRQGXUUç LQ VROLWDULD XQD GHOOH GXH LPEDİ  
İ2ELHWWLYR GL WXWWR TXHVWR VWLPRODUH H İDU FDSLH OİLPSRUWDQJD GHOOD ULFH  
SUHFOLQLFD QHO FDPDR GHOOH 0DODWWLH 5DUH D

3HU VFDULFDUH OD ORFDQGLQD GHO SURJHWWR FOLFFD DO VHJXHQWH OLQN /2&\$  
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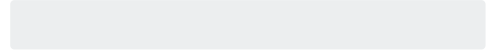
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ODODWWLH 5DUH GHOOD 5HJLRQH &DPSDQLD LQ FROODERUD]LRQH FRQ O.8QLYHU+  
GHOHJD]LRQH GHOOD /HJD 1DYDOH ,WDOLDQD GL 7RUUH \$QQXQ]LDWD H FRQ LO VX!  
FRQRVFNQ]D H OD GLDJQRVL SUHFRFH SHU TXHVWH SDWRORJLH O.LQL]LDWLYD SL  
VROLWDULR FKH GDO SRUWR GL 7RUUH \$QQXQ]LDWD 1\$ DUULYHUDQQR D 0DUVLJC

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PDJJLR 2 È VVDWR SUHVHQVDWR TXHVVD PDWWLQD SUHVVR O.\$XGLWRULXP GH  
L SURJHWWR ',VVLDPR OH YHOH 9HQWR LQ SRSSDSQD GD 15QFRUPD]LRQH O MWXHQD

7XWHOD GHOOD 6DOXWH H LO &HQWUR GL &RRUGLQDPHQWR 0DODWWLH 5DUH GHOOD &DPDQQLD ^/XLJL 9DQYLWHOOLµ H OD GHOHJD]LRQH GHOOD /HJD 0DYDOH 6DQDQD QD G

8QD PDODWWLD VL GHILQLVFH ^UDUDµ TXDQGR OD VXD SUHYDOHQJD LQWHVD FRPH LC VWDELQD ,Q (XURSD OD VRJOLD q ILVVDWD DOOR SHU FHQWR GHOOD SRSROD]I ,O QXPUR GL 0DODWWLH 5DUH FRQRVFLXWH H GLDJQRVWLFDW RYFLOOD WUD OH VFLHQJD H LQ SDUWLFRODUH FRQ L SURVLPVEXGHQD SDULQD GHOHVLQDSDQFKS PDODDGLRQL GL SHUVRQH LQ ,WDOLD H DGGLULWXXUD GHFLQH GL PLQRQL LC /D SRVLELQWj GL DWXDUH LQWHUYHQWL WHUDSHXWFL LQ IDVH LQL]LDQH SXz PL. WDOH PRWLYR q IRQGDPHQWDOH SURPXRYHUH OD FRQRVFLHQJD H OD GLDJQRVL SUHFR

^1HJOL XOWLPL DQQL OD 5HJLRQH &DPDQQLD KD IDWR RQRUPL SDWWUD QDUDQWQD QD B PLUDWD DOOD ULRUJDQL]D]LRQH GHOOD UHWH H DOOD FRVWUX]LRQH GL SHUFRUVL VRWW \$QDQD 3RVWLUHOLVRUWH \*HQHUDOH 7XWHOD GHOOD 6DOXWH 7XWUR ULHQDPRQD DWUDYHUVR O-HPDQD]LRQH GL GHFUHWL YROWL DOO-DSSURYD]LRQH GHO 3LDQR 5 VWDWR ULRUJDQL]DWR LO &HQWUR GL &RRUGLQDPHQWR 0DODWWLH 5DUH FKH KD ^ GLUH]LRQH GHO 3URIHVVRU \*LXVSSH /LPRQJHOOL 4XHVWR SURJHWWR ULHQWUD L GLQIRUPD]LRQH H VHQLLELQ]D]LRQH WHPL SHU QRL GL IRQGDPHQWDOH LPSRUWDQ

^,VVDPR OH YHOH 9HQWR LQ SRSSD SHU OD 5LFHUF D WKLQNUDUH q XQ-LQL]LDWLYD GL XQLUH XQD SDVLRQH TXHOOD GHOOD YHOD D XQ ELVRJQR TXDVL XQ-HPHUHQJD GLVDELQWj H GHOH 0DODWWLD FRUWHOD OD SRPXQWVSR LOP SRUHWWRUH &HQWUR &RRUGLQDPHQWR 0DODWWLH 5DUH 5HJLRQLD &DPDQQLD FKLHUDWD FRQ ORUR SHUFRQW DPQLRVR D FKHSHGUj LPSHQDWL L &HQWUL GL FRRUGLQDPHQWR GHOOD O-HPHQW FRPXQH GL ^LVVDUH OH YHOHµ SRUWDQGR DYDQWL XQ PHVWDJLR SHQVD UDUR SHQV

^D SUHYHQ]LRQH H O-LQIRUPD]LRQH VRQR IRQGDPHQW D GLSHUWRQD FXUDWRUHQHQDOD B &DPDQQLD ^/XLJL 9DQYLWHOOLµ FRQLQR]BWWLH GL TXHVWR JHQHUH FKH YDQQR LQ TXHV DQ]L YDORUL]DWH H LQFUHPHQWDWH 3ODXGR GXQTXH DOO-LGHD GHL QRWUL GRF

^LQL]LDWLYDPR OH YHOH 9HQWR LQ SRSSDSSHHV HQH 5LD SDUDW HQKD QNLUQXHH L PEDUFD] FKH GDO SRUWR GL 7RUH \$QQXQLDWD 1\$ DUULYHUDQQR D 0DUVLJOLD GRSR FLUFD FRQ OD 5HJLRQH /D]LR 7RVFDQD H /LXULD

^D WUDYHQDWD XJQR DDUQD]LDQD FDWD GD GLYHUVH LQL]LDWLYH H LQFRWUL LQ I SURPXRYHUH OD ULFHUF VXOOH PDODWWLH UDUH \$O ILQH GL UDJLXQJHUH H VHQLLELQ]DUH XQD SODWHD SL• YDVWD VDUj SRVLELC VLWVSV VLWR OLEHUR LW FRPH

^\$EELDPR VFHOWR LO PDUH FRPH YHLFROR GL FRPXQLFD]LRQH H GVISXQWGD HQLODX 3UHVLGHQWH /HJD 1DYDOH ^HOHJD]LRQD FRUWHOD QDQD]LDQD WUDLQD LO PDUH VL DYDQWL O-GHD GHO PDUH JXDULWRUH JUD]LH DO VXR SRWHUH WDXPDWXUJLFR

^6RQR IHOLFH GL UHQGHUH FRQHWVDRHSDYLRQRVFLDQDµ GLQDULR GL &KLUXUJLD 7R GHOOD &DPDQQLD ^/XLJL 9DQYLWHOOLµ QRQFKp DSSDVLRQDWR YHQLWVWEKR BRQV VWLPRODUH H IDU FDSLUH O-LPSRUWDQD GHOOD ULFHUF FOLQLFD H SUHFOLQLFD QH

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SHUFRUVR FRQ YDULH WDSSH RJQXQD GHOOD DVI  
LQIRUPDJLRQH H VHQVLELOLJJDJLRQVXQXWVROGHOH PDODWWLH UDUH

È VWDWR SUHVHQWDR QHOOT\$XGLWRULXP GHOOD 5HJLRQH &DPSDQLD  
YHOH 9HQWR LQ SRSSD SHU OD 5LFHUFD WKLQNUDUH' FDPDSDJQD GL LQIRU  
'LUHJLRQH \*HQHUDOH GHOOD 7XWHOD GHOOD 6DOXWH H LO &HQWUR GL &  
5DUH GHOOD 5HJLRQH &DPSDQLD LQ FROODERUDJLRQH FRQ O18QLYHUVI  
&DPSDQLD 3/XLJL 9DQYLWHOOL' H OD GHOHJDJLRQH GHOOD /HJD 1DYDO  
\$QQXQJLDWD H FRQ LO VXSSRUWR GL 0RWRUH 6DQLWj

8QD PDODWWLD VL GHILQLVFH 3UDUD' TXDQGR OD VXD SUHYDOHQJD LQWHV  
SUHVHQWL VX XQD GDWD SRSRODJLRQH QRQ VXSHUD XQD VRJOLD VWDELOI  
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FLIUD FKH FUHVH FRQ O1DYDQJDUH GHOOD VFLHQJD H LQ SDUWLFRODU  
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DGGLULWXXUD GHFLQH GL PLOLRQL LQ WXWWD (XURSD

/D SRVVLELOLWj GL DWWXDUH LQWHUYHQWL WHUDSHXWFLFL LQ IDVH  
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