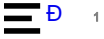


Sommario Rassegna Stampa

| Pagina | Testata | Data | Titolo | Pag. |
|--------|----------------------|------------|---|------|
| | Rubrica | | ISSIAMO LE VELE - 6 giugno 2022 | |
| | Adnkronos.com | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 2 |
| | Giornalesanita.it | 07/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 6 |
| | Inautilus.it | 07/06/2022 | <i>Lega Navale Italiana per la sensibilizzazione sulle malattie rare: partita l'iniziativa Issiamo le v</i> | 8 |
| | Italiavela.it | 07/06/2022 | <i>Lega Navale Italiana per la sensibilizzazione sulle malattie rare: partita l'iniziativa Issiamo le v</i> | 10 |
| | Lagone.it | 07/06/2022 | <i>Lega Navale Italiana "in campo" per la sensibilizzazione sulle malattie rare</i> | 11 |
| | Nonsolonautica.it | 07/06/2022 | <i>Issiamo le vele! Regata della Lega Navale contro le malattie rare</i> | 13 |
| | Pressmare.it | 07/06/2022 | <i>Issiamo le vele: LNI per la sensibilizzazione sulle malattie rare</i> | 15 |
| 25 | Roma | 07/06/2022 | <i>"Issiamo le vele per la ricerca"</i> | 17 |
| | Affaritaliani.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 18 |
| | Gazzettadinapoli.it | 06/06/2022 | <i>Issiamo le vele, parte da Torre Annunziata il progetto per sensibilizzare sulle malattie rare.</i> | 20 |
| | Ilgiornaledelsud.com | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 21 |
| | Ilgiornaleditalia.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 22 |
| | Informazione.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 25 |
| | Intopic.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 28 |
| | Lasicilia.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 30 |
| | Lifestyleblog.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 33 |
| | Lostrillone.tv | 06/06/2022 | <i>Da Torre Annunziata e' partito il progetto 'Issiamo le vele per la ricerca'</i> | 35 |
| | Metamagazine.it | 06/06/2022 | <i>Issate le vele per la ricerca sulle malattie rare</i> | 38 |
| | Mondosalento.com | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 41 |
| | Money.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 42 |
| | Motoresanita.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 45 |
| | Sbircialanotizia.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 48 |
| | Tiscali.it | 06/06/2022 | <i>Issate le vele per la ricerca delle malattie rare!</i> | 52 |
| | Informazione.it | 01/06/2022 | <i>Invito stampa - Issiamo le vele! Vento in poppa per la ricerca #thinkrare - 6 giugno 2022, Ore 10</i> | 54 |
| | Intopic.it | 01/06/2022 | <i>Invito stampa - Issiamo le vele! Vento in poppa per la ricerca #thinkrare - 6 giugno 2022, Ore 10</i> | 57 |



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SRUWL FKH YHGUDQQR OD SDUWHFLSD]LRQH GL DVVRFLD]LRQL GL FDWHJRULD SURIHVVL
LVWLWX]LRQL DO ILQH GL VHQVLELOLJ]DUH VXOOH PDODWWLH UDUH

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TORRE ANNUNZIATA Partite dal porto due barche a vela: gireranno l'Italia per la sensibilizzazione sulle malattie rare

«Issiamo le vele per la ricerca»

TORRE ANNUNZIATA. Sono partite dal porto di Torre Annunziata due barche a vela, per portare lungo le coste italiane, arrivando fino a Marsiglia, il messaggio che è importante fare conoscere le malattie rare, che sono cruciali la diagnosi precoce per giungere ad una cura tempestiva della malattia e la ricerca scientifica per trovare nuove possibilità di cura. Le malattie rare e i malati rari sono al centro dello straordinario progetto "Issiamo le vele! Vento in poppa per la Ricerca #thinkrare", la campagna di informazione attuata dalla Direzione Generale della Tutela della Salute e il Centro di Coordinamento Malattie Rare della Regione Campania, in collaborazione con l'Università degli Studi della Campania "Luigi Vanvitelli" e la Delegazione della Lega Navale Italiana di Torre Annunziata, con il supporto di Motore Sanità e con il contributo incondizionato di Amicus Therapeutics, Chiesi, Takeda e Medisol. Le due barche a vela sono condotte in solitario dal chirurgo Mario Santini, 70 anni, Professore Ordinario di Chirurgia Toracica dell'Azienda ospedaliera universitaria "Luigi Vanvitelli" di Napoli e dall'imprenditore campano Rosario Gracco, 74 anni, che dal Porto di Torre Annunziata (Na) arriveranno a Marsiglia (il 5 luglio) dopo circa 20 tappe, tra cui Roma (14 giugno), Livorno (21 giugno), Genova (27 giugno), grazie alla collaborazione con la Regione Lazio, Toscana e Liguria.

«Siamo felicissimi di intraprendere questa grande sfida - hanno spiegato il professor Mario Santini e l'imprenditore Rosario Gracco -. Ci accomuna non solo l'età ma anche il grande amore per la vela. È un anno che ci stiamo preparando per questo straordinario evento che unisce la passione per la vela con l'aspetto sociale». Paura? «Certamente - ha confessato il Professor Santini -; andare per mare è come entrare in sala operatoria, significa aver previsto tutto per affrontare ogni situazione. Ci auguriamo che questo progetto possa permettere la realizzazione di borse di studio per un ricercatore di Napoli e un ricercatore di Marsiglia affinché questo gemellaggio permetta di far confluire competenze e saperi per la ricerca di nuove cure per i malati rari». «Con #thinkrare questo progetto ci ricorda di pensare alle malattie rare perché queste patologie hanno un percorso che va dal sospetto alla diagnosi alla presa in carico del paziente. Purtroppo, però, tale percorso si rivela molto spesso tortuoso e questo crea una serie di problematiche ai pazienti e alle loro famiglie con una diagnosi tardiva che arriva a sette anni», ha spiegato Giuseppe Limongelli, direttore del Centro di Coordinamento Malattie Rare di Regione Campania. «Questo progetto ci sta molto a cuore e si inserisce nel quadro delle attività che abbiamo messo in campo per potenziare la rete dell'assistenza sanitaria per le

malattie rare», le parole di Antonio Postiglione, direttore generale per la Tutela della Salute e il Coordinamento del Sistema Sanitario Regionale di Regione Campania. «Questo progetto - ha aggiunto Pietro Buono, dirigente Staff tecnico Operativo Salute Regione Campania - nasce da una importante esigenza, quella di sensibilizzare le istituzioni e l'opinione pubblica sulle malattie rare e dare una mano alle famiglie dei pazienti. Per le malattie rare, che tanto rare non sono in quanto raggiungono il 6-8% dei pazienti malati in Italia, è necessario, oltre alla legge e al Coordinamento regionale e nazionale, porre un'attenzione specifica su tutte le esigenze dei malati rari. Sono convinto che questo viaggio ci porterà sicuramente ad una maggiore consapevolezza di queste malattie». «La Lega navale di Torre Annunziata si è resa promotrice di organizzare la logistica di questa straordinaria traversata per la diffusione dei campanelli di allarme delle malattie rare - ha concluso Antonella Giglio, presidente Delegazione Lega Navale di Torre Annunziata (Na) -. Il mare ci permetterà di toccare i porti delle coste laziali, toscane e liguri fino ad arrivare a Marsiglia e di organizzare in ogni attracco eventi di promozione sulle malattie rare al fine di coinvolgere tutte le famiglie e fornire consigli utili affinché possano affrontare al meglio il percorso delle malattie rare».



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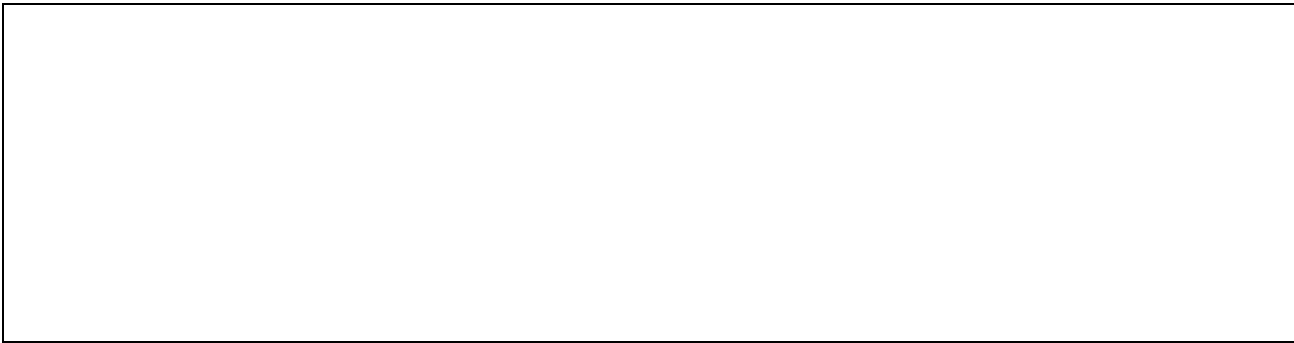
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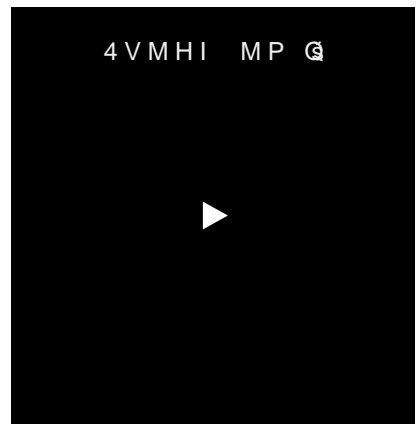
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/H PDODWWLH UDUH H L PDODWL UDUL VRQR DO FHQWUR GHOOR VWUDRUGLQDULP SURJHW
YHOH 9HQWR LQ SRSSD SHU OD 5LFHUFV WKLQNUDUH' OD FDPDSDJQD GELW&XRYM&SRQHM DI
GDOOD 'LUH]LRQH *HQHUDOH GHOOD 7XWHOD GHOOD 6DOXWH H LO &HQWUR GL &RRUGLQDP
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9DQYLWHOOL' GL 1DSROL H GDOO...
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SHU PDUH q FRPH HQWUDUH LQ VDOD RSHUDWRULD VLJQLILFD...
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UHDOLJJDJLRQH GL ERUVH GL VWXGLR SHU XQ ULFHUFDWRUH...
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FUHD XQD VHULH GL SUREOHPDWLFKH DL SDJLHQWL H DOOH ORUR IDPLJOLH FRQ XQD GLDJ...
FKH DUULYD D VHWWH DQQL ± KD VSLHJDWR *LXVHSSH /LPRQJ...
&RRUGLQDPHQWR 0DODWWLH 5DUH GL 5HJLRQH &DPSDQLD...
FUHDUH GHL SHUFURVL SHU OH SDWRORJLH UDUH H OD UHJLRQH &DPSDQLD KD FRVWUXLW...
SHUFURVR JHQHUDOH QHO 3LDQR UHJLRQDOH 0DODWWLH UDU...
FRPLQLDQGR D GHFOLQDUH SHUFURVL SHU VSHFLILFKH PDOI...
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DEELDPR PHVVR LQ FDPSSR SHU SRWHQJLDUH OD UHWH GHOO...
PDODWWLH UDUH ± KD VSLHJDWR \$QWRQLR 3RVWLJOLRQH 'LUHWWRUH *HQHUDOH SHU OD ;...
6DOXWH H LO &RRUGLQDPHQWR GHO 6LVWHPD 6DQLWDULR 5H...
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ORQDOGL FRQ XOWHULRUL ILQDQJLDPHQWL FRQ OD VSHUDQJD...
O...
SHUIHJLRQDWR GXH 3'7\$ PHVVR LQ FDPSSR XQ...
PHGLFLQD JHQHUDOH H VLDPR LQ FRQLQXR FRQWDWWR FRQ OH DJLHQGH VDQLWDULH DII...
WHVWLPRQLQR TXDOL VRQR L SXQWL GL IRUJD H L SXQWL GL GHEROHJJD LQ PRGR FKH SRV...
SDUWLUH FRQ LQLJLDWLYH VHPSUH SL• GLUHWWH DO SRWHQJLDPHQWR GHOO...
UDUL 6LDPH VLFXUL FKH ODYRUDQGR LQ VLQHUJLD FRQ JOL VWDNHKROGHUV GHO VHWWRU...
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OH LVWLWXJLRQL H O...
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GHL SDJLHQWL PDODWL LQ ,WDOLD q QHFHVVDULR ROWUH DOOD OHJJH H DO &RRUGLQDPH...
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.^iiHx \m\xP;l;xÀ ;Á°x...xNPmN^A^x••••xÈx-^A^xf;iPIHxF;Zx)^iI^xFPx.^iiH \m\xP;l;xÀ ;ÁxFmHxC;iDOHx;xrHZ;°xfHixf^iI;iHxZm\N^xZHxD^jIHxPI;ZP;\H° ;iiPr;\F^xMP^A^x;x ;ijPNZP;°xPZx[Hjj;NNP^xDOHxLxP[f^iI;\IHxM;iHxD^A^jDHiHxZH [;Z;IIPHxi;iH°xDOHxj^A^xDimDP;ZPxZ;xFP;N^jPxfiHD^DHxfHixNPm\NHiHx;Fxm\;xDmi; IH[fHjIPr;xFHZZ;x[;Z;IIP;xHxZ;xiPDHiD;xjDPH\IPMPD;xfHixIi^r;iHx\m^rHxf^jPCPZPI? FPxDmi;~

Hx[;Z;IIPHxi;iHxHxPx[;Z;IPxi;iPxj^A^x;ZxDH\Ii^xFHZZ^xjIi;^iFP\;iP^xfi^NHII^ Í jjP;[^xZHxrHZH´x4H\I^xP\xf^ff;xfHixZ;x„PDHiD;x»IOP\Yi;iHÎ°xZ;xD;[f;N\;xFP P^M^i[;xP^A^Hx;IIm;l;xF;ZZ;x PiHxP^A^Hx H\Hi;ZHxFHZZ;x.mIHZ;xFHZZ;x-;ZmIHxHxP H\Ii^xFPx ^A^iFP\;[H\I^x ;Z;IIPHx„;iHxFHZZ;x„HNP^A^Hx ;[f;\P;°xP\ D^ZZ;C^i;xP^A^HxD^A^xZÐ\PrHijPI?xFHNZPx-ImFPxFHZZ;x ;[f;\P;xÍ mPNP4;\rPIHZZPÎxI Z;x HZHn;xP^A^HxFHZZ;x HN;x ;r;ZHx l;ZP;\xFPx.^iiHx \m\xP;l;°xD^A^xPZxjmff^iI^ FP&I^iHx-;\P^HxD^A^xPZxD^A^IIPCmI^xP\D^A^FPxP^A^;I^xFPx [PDmjx.OHi;fHmIPDj° OPHjP°x.;YHF;xHx HFPj^Z~

HxFmHxC;iDOHx;xrHZ;xj^A^xD^A^F^IiHxP\xj^ZPI;iP^xF;ZxDOPimiN^x ;iP^x-;\IP\P°x†• ;\P°x)i^MHjj^iHx!iFP\;iP^xFPx OPimiNP;x.^i;DPD;xFHZZÐ xPH\F;x^jfhf;ZPHi; m\PrHijPI;iP;xÍ mPNP4;\rPIHZZPÎxFPx ;f^ZPxHxF;ZZÐP[fiH\FPI^iHxD;[f;\^x,^j;iP^ i;DD^°x†fx;\IP°xDOHxF;Zx)^iI^xFPx.^iiHx \m\xP;l;xÀ ;Áx;iiPrHi;\^x;x ;ijPNZP; ÀPZx„xZmNZP^ÁxF^f^xDPiD;x••xI;ffH°xIi;xDmPx,^[;xÀ€fxNPmN^A^Á°x Pr^i^A^xÁ•€xNPm H\^r;xÁ•†xNPmN^A^Á°xNi;xPHx;ZZ;xD^ZZ;C^i;xP^A^HxD^A^xZ;x„HNP^A^Hx ;xP^°x.^jD;\; Hx PNmiP;~

Í-P;[^xMHZPDPjjP[PxFPxP\Ii;fiH\FHiHxhmHjI;xNi;\FHxjMPF;xÈxO;\^xjfPHN;I^xD^A^ H\ImjP;j[^xPZx)i^MHjj^ix ;iP^x-;\IP\PxHxZÐP[fiH\FPI^iHx,^j;iP^x i;DD^xÆ~x P ;DD^[m\;x^A^xj^AZ^xZÐHI?x[x;x\DOHxPZxNi;\FHx;[^iHxfHixZ;xrHZ;~x xm\x;\^ DOHxDPxjIP;[^xfiHf;i;\F^xHixhmHjI^xjIi;^iFP\;iP^xHrH\I^xDOHxm\PjDHxZ; f;jjP^A^HxfHixZ;xrHZ;xD^A^xZÐ;jfHII^xj^ADP;ZHÎ~x);miH¶xÍ Hil;[H\IHxÈxO; D^AMHjj;I^xPZx)i^MHjj^ix-;\IP\PxÆ±x;\F;iHxfHix[iHxLxD^A^HxH\Ii;iHxP\xj;Z; ^fHi;I^iP;°xjPN\PMPD;x;rHixfiHrPjI^xImII^xfHix;MMi^I;iHx^N^PxpjPlm;xP^A^H~x P ;mNmIP;[^xDOHxhmHjI^xfi^NHII^xf^j;xfHi[HIIHiHxZ;xiH;ZPx;xP^A^HxFPxCA^ijHxFP jImFP^xfHixm\xiPDHiD;I^iHxFPx ;f^ZPxHxm\xiPDHiD;I^iHxFPx ;ijPNZP;x;MMP\I

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hmHjI^xNH[HZZ;NNP^xfHi[HII;xFPxM;ixD^MzmPiHxD^[fHII\XHxHxj;fHiPxfHiXZ;
iPDHiD;xFPx\m^rHxDmiHxfHixPx[;Z;IPxi;iPî

í \x»IOP\Yi;iHxhmHjI^xfi^NHII^xDPxiPD^iF;xFPxfH\j;iHx;ZZHx[;Z;IIPHxi;iH
fHiDOIxhmHjIHxf;I^Z^NPHxO;\x^m\xfHiD^ij^xDOHxr;xF;Zxj^jfHII^x;ZZ;xFP;N\^jP
;ZZ;xfiHj;xP\xD;iPD^xFHZxf;xPH\IH^x)mili^ff^°xfHib°xI;ZHxfHiD^ij^xjPxiPrHZ;x[^ZI^
jfHjj^xI^iIm^j^xHxhmHjI^xDiH;xm\;xjHiPHxFPxfi^CZH[;IPDOHx;Pxf;xPH\IPxHx;ZZH
Z^i^xM;[PNZPHxD^x\m\;xFP;N\^jPxI;iFPr;xDOHx;iiPr;x;xjHIIHx;\P^xÈxO;xjfPHN;I^
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,HNP^Hx ;[f;\P;xÆ^-x ðLxfHiI;\I^xZ;x\HDHjjPI?xFPxDiH;iHxFHPxfHiD^ijPxfHiXZH
f;I^Z^NPHxi;iHxHxZ;xiHNP^Hx ;[f;\P;xO;xD^jlimPI^x\m\xfHiD^ij^xNH\Hi;ZHx\HZ
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FHDZP\;iHxfHiD^ijPxfHiXjfHDPMPDOHx[;Z;IIPHxi;iH°xHx^NPNP^Hx;CCP;[^xjHIIH
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P[f^iI;\IPxiPjmZI;IPxP\jPH[Hx;\DOHx;ZZHx jj^DP;xP^PxfFPxf;xPH\IPî

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DOHx;CCP;[^x[Hjj^xP\xD;[f^xfHiXf^IH\Xp;iHxZ;xiHIIHxFHZZð;jjPjIH\X;xj;\PI;iP;
fHiXZHx[;Z;IIPHxi;iHxÈxO;xjfPHN;I^x \I^P^x)AjIPNZP^H°x PiHII^iHx H\Hi;ZHxfHi
Z;x.mIHZ;xFHZZ;x-;ZmIHxHxPZx ^iFp\;[H\I^xFHZx-PjIH[;x-;\PI;iP^x,HNP^;\ZHxFP
,HNP^Hx ;[f;\P;xÆ^-x ;xf^D^x;CCP;[^xf^IH\Xp;I^xPZx H\li^x,HNP^;\ZH
jPlm;I^xfiHjj^xPZxfiHjPFP^x^jfHF;ZPHi^x ^\;ZFPxD^x\mZIHIP^iP^MP\;\P;[H\IP°xD^\
Z;xjfHi;\x;xFPxD^IP\m;iHx;x[PNZP^i;iHxZð;jjPjIH\X;xrHiJ^xhmHPxf;xPH\IPxDOH
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jP;[^xP\xD^IP\m^x^D^I;II^xD^xZHx;xPH\FHxj;\PI;iPHx;MMP\DOIxDP^IHjIP[^P^\
hm;ZP^j^x^xPxfm\IPxFPxM^ix;xHxPxfm\IPxFPxFHC^ZHxx;xP\X[^F^xDOHxf^jjP;
f;iIPiHxD^xP\^xP;IPrHxjH[fiHxfPqxFPiHIIHx;Zxf^IH\Xp;[H\I^xFHZZð;jjPjIH\X;xFHP
[;Z;IPxi;iP^-x-P;[^xjPDmiPxDOHxZ;r^i;\F^xP\XjP\HiNP;xD^xNZP^jI;YHO^ZFHiJxFH;
jHII^iHxD^IP\mHiH[^x;Fx;MMHi[;iHxm\;xj;\PI?xFPxhm;ZPI?xP\XiHNP^H
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hmHZZ;xFPxjH\jPCPZPxx;iHxZHxPjIPImxP^P^xHxZð^fP^Hx^fmCCZPD;xjmZZHx[;Z;IIP
F;iHxm\;x[;\^x;ZZHxM;[PNZPHxFHPxf;xPH\IP^x)HixZHx[;Z;IIPHxi;iH°xDOHxI;\I^xi;iH
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m\ð;IIH\xP^HxjfHDPMPD;xjm^ImIIHxZHxHjPNH\XHx^FHPx[;Z;IPxi;iP^-x^x^D^rP\I^xDOH
hmHjI^xrP;NNP^xDPxf^iIHi?xjPDmi;[H\IHx;Fxm\;x[;NNP^iHxD^j;fHr^ZHxx;xFP
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Z^NpjIPD;xFPxhmHjI;xjli;^iFp\;iP;xli;rHiJ;l;xfHixZ;xFPMMjP^Hx^FHPxD;[f;\HZZPxFP
;ZZ;i[Hx^FHZZHx[;Z;IIPHxi;iHxÈxO;xD^DZmj^x \I^HZZ;x PNZP^°x)iHjP^FH\I^
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FPx^iN;\Pxx;iHxP\^N\^P;x;Ili;DD^xHrH\IPxFPxfi^[^xP^HxjmZZHx[;Z;IIPHxi;iHx;ZxMP\H

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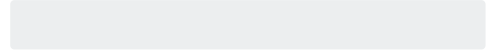
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^\Hu^RLxP\jHiI^xFPx ^iHtP\MA^PI°xIHj!;l;xNP^i\;ZPjIPD;x;xIH[;xHD^^[F B Z x H i C P m \ \ Z P x i P P x x ; i f i ; i P x x ; x B ^ i H x x F H Z x • ,



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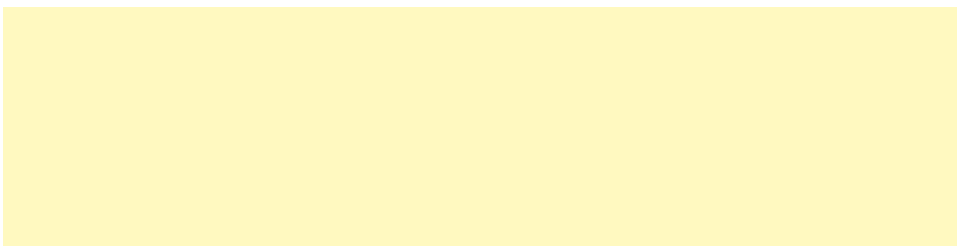
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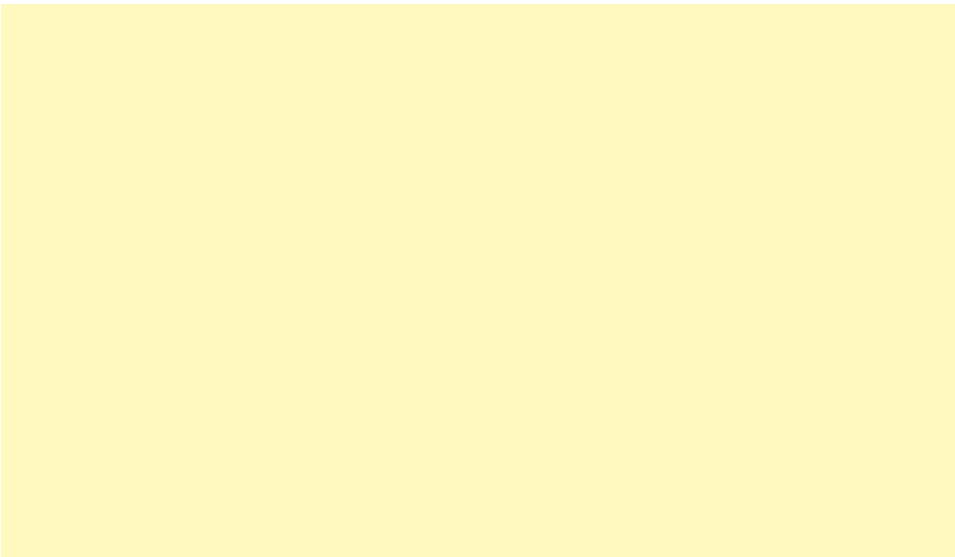
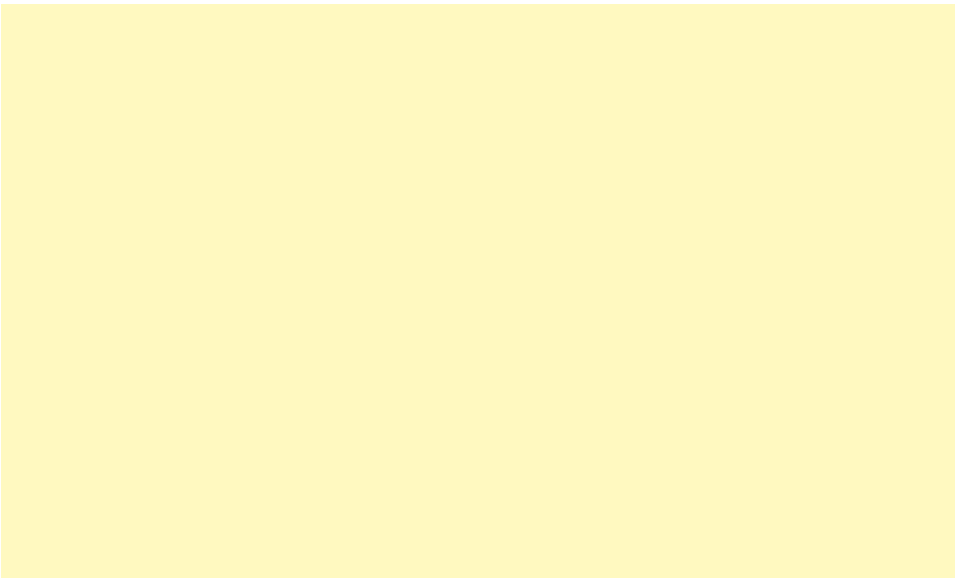
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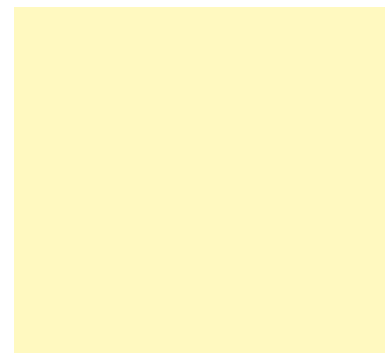
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